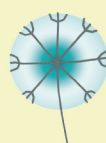


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DIRECTRICES ANTICIPADAS Y PLANIFICACIÓN ANTICIPADA DE LOS CUIDADOS. UNA TAREA PARA ALGORITMOS PREDICTIVOS

Fernando Lolas Stepke¹

En discusiones sobre legislación relativa a las disposiciones que las personas desean ver implementadas para situaciones de peligro vital el acento recae en eufemismos como “muerte digna” o “muerte médicamente asistida”. El público en general suele hablar de leyes sobre eutanasia, despenalización de las acciones médicas que aceleren la muerte, autonomía de las personas para decidir sobre los cuidados que aceptarían y otras materias.

Especial atención merecen las **directrices anticipadas** (*advance directives*) o “testamentos vitales”, expresiones de deseos que se manifiestan antes de las situaciones críticas del final de la vida. Pueden ser documentos oficiales, certificaciones o expresiones a allegados, que pueden sufrir revocación o modificaciones según las circunstancias. El origen de los “*living wills*” (testamentos o voluntades anticipadas) puede rastrearse hasta los años sesenta del siglo pasado y la primera concreción jurídica fue en California, Estados Unidos, asociada a las discusiones provocadas por los casos de Karen Quinlan, Nancy Cruzan y Terry Schiavo.

Las voluntades anticipadas están sujetas a varios supuestos. Primero, que la persona que las formula esté en condiciones de hacerlo desde el punto de vista de su capacidad o competencia cognitiva. Segundo, que pueda ser objeto de revisión a lo largo de la vida, ya que las actitudes y creencias pueden cambiar. Tercero, que las personas o sus allegados puedan representarse más o menos coherentemente el escenario en el cual debieran aplicarse. Finalmente, que su existencia sea conocida por las instituciones sanitarias o personas en condiciones de representar fielmente los deseos de quienes formulan tales deseos o preferencias. Ocurre a veces que familiares o amistades intervienen en momentos cruciales, a veces contradiciendo lo expresado con anterioridad, lo que pesa sobre las decisiones del personal sanitario. En el ámbito público, motivos religiosos o ideológicos tienen importancia para la discusión.

La idea de una **planificación anticipada de los cuidados** (*advance care planning*) es más inclusiva que la de directrices anticipadas. Se trata de procesos en los cuales las personas pueden manifestar, en conjunto con sus otros significativos y el personal sanitario, sus preferencias sobre cómo desearían ser tratadas aun en casos en que no exista posibilidad de muerte sino, por ejemplo, de incapacidad por demencia o enfermedades mentales graves.

Los dilemas éticos planteados por estas alternativas no solamente se refieren a la autonomía de las personas. Aparte de la adecuada evaluación de capacidades cognitivas, es necesario considerar el significado y el sentido de la vida individual en su contexto cultural, social y económico. Hay quienes sugieren que cuidados paliativos eficaces harían innecesario regular la forma en que se desee afrontar la muerte física y la muerte social. Se podría argumentar que las preferencias que se manifiestan con anticipación no reflejan la realidad de una contingencia inesperada y que la persona cambia a lo largo de la vida, de modo que no es la misma cuando se enfrenta a trances o situaciones imprevisibles. El factor esperanza no debe ser desestimado, como tampoco la noción arraigada en los profesionales sanitarios de que toda muerte o discapacidad permanente son fallas personales o del sistema sanitario y deben ser combatidas.

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La **autonomía decisional** no puede discutirse aisladamente. Es un concepto complejo que debe ser tratado en el marco de las relaciones interpersonales. También involucra las creencias de las personas y la confianza que tengan en los sistemas sociales en los cuales se insertan. Toda persona pertenece simultáneamente a muchos de ellos, de modo que la noción de identidad personal debe considerar este factor relacional. Tanto morir como sufrir una enfermedad mental incapacitante no es solo asunto individual; involucra a otros pues incluso quienes viven en aislamiento o soledad son parte de las comunidades.

La implementación de registros electrónicos apoyados por una adecuada logística algorítmica permitiría perfeccionar la planificación anticipada de cuidados e introducir rápida y confiablemente modificaciones según las circunstancias. El universo valórico de los grupos humanos puede sufrir modificaciones dependiendo de la autopercepción y de cambios en el cuidado de la salud. Un posible uso de la lógica algorítmica es brindar una **anticipación de escenarios** considerando una cantidad de variables muy superior a la que se tiene en cuenta al momento de expresar deseos, preferencias o necesidades. De esa forma, la planificación anticipada de cuidados puede enriquecerse con un factor de “*imaginación proléptica*” que permita elegir más de un curso de acción según las circunstancias. Es difícil que las personas puedan formarse ideas claras sobre los escenarios que enfrentarían, los apoyos sociales que necesitarían y los recursos a los que tendrían acceso. Sin embargo, la “**inteligencia artificial**” **predictiva**, disponiendo de informaciones sobre diversos aspectos o dimensiones puede predecir o prefigurar contingencias de modo vívido y comprensible. La formulación de una planificación anticipada de cuidados así ampliada sería más flexible y probablemente más efectiva.

“HOW TO LEAD OUR LIVES?” ADVANCE DIRECTIVES (ADS) IN AN ARISTOTELIAN APPROACH: AN ESSAY

José Dimas D’Avila Maciel Monteiro¹, Elcio Luiz Bonamigo², Rui Nunes³

Abstract: The question “how to lead our lives?” is a question about which life to live and is at the center of Aristotle’s ethical investigations in *Nicomachean Ethics*. Such a question seems not to get old, particularly when we express, in advance, decisions about future medical care to consent to or refuse, in advance directives (ADs), when we are unable to decide. The purpose of this investigation is to philosophically approach ADs from the question “how to lead our lives?”, admitting three possible approaches to aspects of Aristotle’s ethical investigation: 1st) emotions and ADs; 2nd) deliberation, deliberate choice, *phronesis* and ADs; 3rd) “How to lead our lives?” and ADs. It is concluded that a) the purpose of human life, according to Aristotle, is not simply to live, but to live humanly; b) the answer to the question “how to lead our lives?”, considering the categories of happiness (*eudaimonia*), emotions, virtues, practical wisdom (*phronesis*), deliberation, deliberate choice, and action, also involves the answer to the question about death and dying; c) Aristotle’s ethical investigation may be an alternative, although limited, to address ADs without the necessary appeal to moral rules.

Keywords: Bioethics, advance directives, personal autonomy, deliberation

“¿Cómo dirigir nuestras vidas?” Directrices anticipadas (DA) desde un enfoque aristotélico: un ensayo

Resumen: La pregunta “¿cómo llevar nuestras vidas?” es una cuestión sobre qué vida vivir y está en el centro de las investigaciones éticas de Aristóteles en la *Ética a Nicómaco*. Tal pregunta no parece envejecer específicamente cuando expresamos, de antemano, decisiones sobre la atención médica futura para consentir o rechazar, en directivas anticipadas (DA), cuando no somos capaces de decidir. El propósito de esta investigación es abordar filosóficamente la DA desde la pregunta “¿cómo vivir nuestra vida?”, admitiendo tres posibles aproximaciones a aspectos de la investigación ética de Aristóteles: 1) las emociones y la DA; 2) deliberación, elección deliberada, *phronesis* y la DA; 3) “¿Cómo llevar nuestra vida?” y el DA. Se concluye que a) el propósito de la vida humana, admitido por Aristóteles, no es simplemente vivir, sino vivir humanamente; b) la respuesta a la pregunta “¿cómo vivir nuestra vida?”, considerando las categorías felicidad (*eudaimonia*), emociones, virtudes, sabiduría práctica (*phronesis*), deliberación, elección deliberada y acción, implica también la respuesta a la pregunta sobre la muerte y el morir; c) La investigación ética de Aristóteles puede ser una alternativa, aunque limitada, para abordar la DA sin la necesaria apelación a reglas morales.

Palabras clave: bioética, directivas anticipadas, autonomía personal, deliberación

“Como conduzir nossas vidas?” Diretivas antecipadas (DA) numa abordagem aristotélica: um ensaio

Resumo: A pergunta “como conduzir nossas vidas?” é uma pergunta sobre qual vida viver e está no centro das investigações éticas de Aristóteles na *Ética a Nicómaco*. Tal pergunta parece não envelhecer, especificamente quando manifestamos, antecipadamente, decisões sobre cuidados médicos futuros a consentir ou a recusar, nas diretivas antecipadas de vontade (DAV), quando não formos capazes de decidir. A proposta desta investigação é abordar, filosoficamente, as DAV a partir da pergunta “como conduzir nossas vidas?”, admitindo três possíveis aproximações a aspectos da investigação ética de Aristóteles: 1ª) emoções e as DAV; 2ª) deliberação, escolha deliberada, *phronesis* e as DAV; 3ª) “Como conduzir nossas vidas?” e as DAV. Conclui-se que a) a finalidade da vida humana, admitida por Aristóteles, não é simplesmente viver, mas viver à maneira humana; b) a resposta à pergunta “como conduzir nossas vidas?”, considerando as categorias felicidade (*eudaimonia*), emoções, virtudes, sabedoria prática (*phronesis*), deliberação, escolha deliberada e ação, envolve também a resposta à pergunta sobre a morte e o morrer; c) A investigação ética de Aristóteles pode ser uma alternativa, ainda que limitada, para abordar as DAV sem o apelo necessário a regras morais.

Palavras chave: bioética, diretivas antecipadas, autonomia pessoal, deliberação

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Introduction

Planning our lives and achieving what we want, even if we are not sure we will achieve it, is a widely accepted idea. It is possible to argue that planning our lives stems from the universal capacity for reflection in choosing which life we should live(1,2). This idea is not new and may lead us to the Aristotelian idea of happiness (“the best life for a man to live”(3), the central object of the *Nicomachean Ethics*(4). However, this is about human happiness, human flourishing, not that of the gods. This is significant, as flourishing (or prospering) limits the scope of our capacities and our world: we are rational and mortal, immersed in contingencies, slaves of the sensations and emotions necessary for our survival. These are the conditions under which we can flourish and achieve any happiness, as well as fail(5).

We are not like the gods, noted Aristotle. They are always happy and blissful, they do not need to enter into contracts, return things received, take risks, or moderate their actions(4:X 8 1178b7-16). This is because they are not subject to contingencies, or circumstances; they don’t inhabit the world of indeterminacy(4:X 8 1178b7-16). Planning our lives and deciding which life to live is an eminently human task and we do it because the future is uncertain(4:VI 2 1039a7-8). This task is given to us by our nature, since all human activities, such as choices and actions, aim at a purpose and that is the good(4:I 2 1094a1-2).

“How to lead our lives?” is the question about which life to live, about happiness, and what is in question is not the knowledge of it, but what concerns the actions that lead to it and how we should practice them. Aristotle links happiness to virtue, as happiness seems to be a virtuous life(4:I 13 1102a5). The virtuous life involves practical wisdom (*phronesis*), emotions, deliberation, deliberate choice, and action.

“How to lead our lives?” is a question that does not get old, as we are continually faced with it, even when we are tempted to control the future, specifically when we express decisions about future medical care to consent or refuse, in advance directives (ADs), when we are unable to manifest them. ADs are an important tool for medical care

because, at the very least, they are an emblem of people’s autonomy and self-determination in relation to their own lives – manifest in their values, desires, and preferences – preventing them from undergoing futile clinical treatments.

Thus, the purpose of this investigation is to philosophically approach ADs from the question “how to lead our lives?”, considering three possible approaches to aspects of Aristotle’s ethical investigation: 1st) emotions and ADs; 2nd) deliberation, deliberate choice, *phronesis* and ADs; 3rd) “How to lead our lives?” and ADs.

Rehabilitation of Aristotle’s ethics in contemporary moral thought

The influence of Aristotle’s ethics on contemporary moral thought is recognized, and the reasons are diverse(2,5-7:330-1,8). Among them, the need to overcome the notion of “moral duty” and the recovery of the Aristotelian notion of “virtue”(6); the importance of Aristotle’s approaches to practical reason (along with those of Plato and the Stoics) and deliberation about how to use reason as a guide in human life, rivalling Kantian and utilitarian models(9:12).

The caveat, however, is that Aristotle has little or nothing to say about issues arising from many of our ethical concerns, and this must also be taken into account(5). Three of them are illustrative: 1st) regarding “living well”, the human Good, there is no rational basis that justifies the analytical identification between human happiness (happiness, prosperity, human well-being) and living according to virtue(5); 2nd) Aristotle does not offer us systems of rules for human actions, that is, he does not provide us with basic normative ethics. This is opposed to what modern thought would expect about the main result of the task of a philosophical ethics, to systematize the principles of human conduct(5,10:150); 3rd) the irreducible link between ethics and the structure of the Greek *Polis* can be an obstacle for Aristotelian ethics to gain a place in our world, since details of the explanation of the virtues presuppose the context of a structure that no longer exists(10:163).

In this sense, some internal difficulties and the limited scope of Aristotle’s ethical investigation, in

relation to contemporary moral conflicts, pointed out by scholars of Aristotle's ethical thought, undo any minimal claim to find in the answer to the question "how to lead our lives?" some trace of a guide to rules of action for ADs. If there are frustrations for anyone approaching Aristotle's ethical investigation, one of them is not finding, in a forceful way, rules of action (11,12). In this sense, following, as a reader, some aspects of his ethics is enough to give credence to MacDowell's consideration of the advantage of studying an important philosopher of another era because it is possible to perceive that we do not need to swim with the tides of our own time (11).

Purpose of human life: the human good, happiness and a peculiar way of living...

If we can plan our lives considering them as a complete life, as a process, is there a purpose for human life? A purpose? If so, what is it? Is it one's own way of living? Is there a better life to be lived? Are there reasons to seek it out? If there is a better life to be lived, then it seems reasonable to pursue it and unreasonable not to pursue it. After all, is there anything better to be desired than to live well? (13). But what does this good consist of?

The clue to investigate such questions is given by Aristotle at the beginning of the *Nicomachean Ethics* (4), starting from a common opinion about human things, that all activity and all investigation, as well as all choice and action, aim at a good, an end. As are many arts and sciences activities, so are their purposes. Medicine is health, just as strategy is victory. However, about our actions, there is a good before all others, a good desired by itself and all other goods are sought in terms of it. If the knowledge of this good brings great influence on human life, then Aristotle undertakes an investigation with the aim of determining what this good is, as well as which science or activity it is the object of. This must be political science, for it embraces all others and its purpose also includes that of others (4:I 1-2). The human good is the end of political science. But still, what does this good consist of?

Aristotle's investigation is faced with another common opinion, that the beautiful and just actions seem varied and vague, and can be consid-

ered in a conventional and unnatural way. The same also happens with goods, since it is observed that some people have already perished because of wealth. Starting from this premise - fine and fair actions seem to be constituted in a conventional way and not in a natural way - Aristotle claims that such an investigation will reach truths in general, approximate lines, as well as goods, since the nature of the subject does not allow more than that (4:I 3 1904b11-27), which is a distinctive aspect of his ethics.

The good, the end to which all actions aim, is identified with happiness. Both common people and sages believe that living well and taking action equal happiness. However, opinions differ about what happiness really is. Some link it to pleasure, wealth, or health; others to honours, and still others to the contemplative life. But these goods seem not to be chosen for their own sake, but chosen for the sake of happiness (4:I 7 1095a218-26). There must be, for Aristotle, something peculiar to the human being, something that distinguishes him. And he concludes that happiness is established as an activity of the soul in conformity with virtue. It involves a certain way of life that spans a lifetime, just as one swallow does not make a summer, just as one day does not make a human being happy (4:I 7 1098a7-19).

It is not just any way of life as noted by Lawrence, but a way peculiar to human beings, acting rationally (thinking and emotions), implying a rational choice and the virtues of that choice. It is what distinguishes us from other living beings. One of the sophistications of the human function, living well or acting well, is that it refers to real living (13). According to Kraut, even if a theory about how to conduct our lives must be submitted to intellectual tests, it must do even more: it must be able to be lived and, in a way, the human good defined by Aristotle points in this direction (14).

A door is opened here to approach, in general terms, an aspect involving ADs. If Aristotle is correct in considering happiness to be living well in a complete life, not episodic, then living in a certain way may also imply dying in a certain way. Perhaps it is less about consenting or refusing treatments in future medical care and more

about which life we want to live. It is less about treatment and more about which life to live.

Virtues, emotions, deliberation, deliberate choice, actions, practical wisdom (*phronesis*) and the prudent person (*phronimos*): what is within reach of our choices and actions?

If living well and being happy involve virtuous actions, then what constitutes happiness? Aristotle's task, after defining happiness as an activity of the soul in accordance with virtue, is to investigate it (4:I 13 1102a6-7). Rather, he approaches the human soul in general terms and divides it into two parts: a rational one; another non-rational. Of this, there are two parts: the vegetative, and the appetitive and desiring, participating in a certain way in reason. The vegetative part is concerned with nutrition and food; the appetitive and desiring partakes, to a certain extent, of reason, for it is capable of obeying reason, as well as capable of not obeying it. If there are people who act well, obeying reason and the rational part of reason, in the same way, they can act against reason. As for virtue, it is also divided into two kinds: intellectual and moral virtues. The first is mostly given by teaching, such as wisdom (*sophia*) and practical wisdom (*phronesis*); the second is given by habit, like generosity, temperance, courage, and justice. These virtues we acquire by their exercise, for we learn to act virtuously by acting virtuously. In the same way, we learn to be courageous by acting courageously. However, the same things that make us courageous can make us vicious, acting cowardly, as we get used to facing dangerous situations or fearing them (4:I 13 1102a25-II I 1103b26).

Aristotle's investigation of virtue proceeds from the premise that it does not aim at theoretical knowledge but at how we become good. Therefore, it is necessary to investigate what they refer to and how we should practice them (4:II 2 1103b27-1104a26). It also starts from an accepted principle: "acting according to right rule" (4:II 2 1103b32). However, it must also be admitted, such an investigation is limited in scope, for what involves particular actions and useful things is not exact. The agent does not have a precept or rule on which he must act as a basis; he will consider the circumstances.

Moral virtues can be destroyed by excess and defect, just as vigour and health can. Too much exercise or too little food destroys vigour and health, and so does too little exercise and too little food. As for courage, he who fears all things becomes a coward; he who fears nothing becomes reckless. Courage, a virtue, is destroyed by excess and defect and preserved by the mean. One who accustoms himself to enduring fears and facing them is courageous, and by acting in this way, he becomes more capable of bearing and facing fears. The brave man rejoices, or at least does not suffer, with the fear he faces; the coward suffers from fears. Thus, the moral virtues relate to pleasure and suffering. Because of this, we do evil deeds; because of that, we stop doing beautiful deeds. And if the moral virtues relate to actions and emotions and if these are accompanied by pleasure and suffering, then it confirms that moral virtues concern pleasure and suffering (4:II 2 1104a11-3 1104b28).

In the direction of understanding what virtue is, Aristotle will investigate whether it is even a certain type of disposition. Regarding the generated states of the soul, virtue must be one of them: emotions, capacities and dispositions. By emotions, Aristotle considers anger, fear, envy, hatred, pity, ambition, among others, and, in general, everything that results from pleasure and suffering; by capacity, the way we are affected by emotions, the capacity to feel pity, to feel hate; by disposition, the way we behave in the face of emotions. Regarding anger, if we feel it excessively, we act badly; if we feel it moderately, we act well. So, the virtues are not emotions, as we are not virtuous or vicious because of emotions. Also, virtues are not capacities, first, because they are independent of deliberate choices, and virtues involve certain choices; second, because we don't say that we are good or bad by the capacity of feeling emotions. It remains for virtue to be a certain type of disposition, and this will be the one by which the human being becomes good, acts well, performing what is proper to him, the human good (4:II 5-6 1107a3).

But what is the nature of moral virtue? What justifies it as a means (middle ground, middle term)? Aristotle considers that over everything that "is continuous and divisible it is possible to take

more, less, or an equal amount, and that either in terms of the thing itself or relatively to us; and the equal is an intermediate between excess and defect" (4:II 6 1106a26-28). By the intermediate, in relation to the object itself, he understands it to be the same in all cases, according to arithmetic proportion. Between 10 and 2, which represent a lot and a little, 6 is the middle term. By the intermediate relative to us, he understands it not to be fixed in all cases. The coach will not prescribe heavy exercise for a beginner athlete, just as he will not indicate light exercise for an experienced athlete. What is excess for one will seem light to another (4:II 6 1106a29-b4). In this sense, one can feel fear, confidence, and anger too much or too little, and both are not the right way to feel, but it is the right way, the middle ground, "to feel them at the time, with reference to the right objects, towards the right people, with the right motive, and in the right way" (4:II 6 1106b20-22). For Aristotle, the virtues are related to emotions and actions, aiming for the middle ground. Missing the target is easy, hitting it is difficult. From this path, virtue is defined by Aristotle as:

is a state of character concerned with choice, lying in a mean, i.e., the mean relative to us, this being determined by a rational principle, and by that principle by which the man of practical wisdom would determine it. Now it is a mean between two vices, that which depends on excess and that which depends on defect (4:II 6 1106b36-a1-4).

If moral virtue is a deliberate choice, what constitutes a deliberate choice? Aristotle's investigation of deliberate choice begins by considering what does not constitute it (4:III 2). It is not common to irrational animals; it is not appetite, since the latter is opposed to the former; it is not wanting, because we don't deliberately choose impossible things. Likewise, they are not opinions. In this sense, it seems that deliberate choices concern the deliberative desire of what is in our power and that they are directed towards an end and the means to that end (12). Aristotle establishes deliberate choice as involving thought and reflection, and seems to refer to that which is chosen in preference to other things (4:2 1112a17).

Deliberate choice is preceded by deliberation. This is a kind of investigation, and Aristotle asks himself about what is possible to deliberate (4:III 3). Not much remains for deliberation. Among those listed by Aristotle, the following stand out: one does not deliberate on eternal objects, the universe, for example; nor in relation to what happens sometimes one way, sometimes another, rains and droughts, for example; One does not deliberate about all human things, as the way for a people to govern itself. The ones that remain are those that are in our power, within our reach to do. Deliberation "is concerned with things that happen in a certain way for the most part, but in which the event is obscure, and with things in which it is indeterminate" (4:III 3 1112b8-10). Deliberation is not about ends, but about means. The purpose of medicine is health, and a doctor does not decide whether or not to achieve this end; he decides what means to use to achieve this end more easily and in the best way. The principle of action is in us, but the object of deliberation is not the end to be attained, but the means conducive to it (4:III 3 1112b12-1113a8). Price considers deliberation to be an intentional activity directed towards an intentional action (15).

The object of deliberation is the same as that of deliberate choice, but that of deliberate choice is determined by deliberation (4:III 3 1113a3-4). However, Bobzien points out that, although the things in our power are common among them, the object of deliberate choice is not the same as that of deliberation, since the object of deliberation is what the agent deliberates about; that of deliberate choice is what the agent came to choose. The first is undefined; the second is determined. Deliberation offers the courses of action resulting from the investigation. Deliberate choice decides on the course of action established by the deliberation or not, and this will imply voluntary action. Voluntary actions are the object of praise or censure; the involuntary ones of forgiveness and sometimes pity. These happen because they are forced or out of ignorance and their principle is external to the agent; and no responsibility can be attributed (12). Voluntary actions are those whose principle of action is in the agent, it is in his power to act or not (4:III 1110a15-18). Thus, human agency involves deliberate choice and, through it,

the connection between voluntary actions, virtues, and vices is drawn(12).

If it is right for us to choose the middle ground (mean), avoiding excess and lack, and if this concerns the right rule (right reasoning), then what is the nature of this? This is Aristotle’s investigation in Book VI of the *Nicomachean Ethics*(4): what is the right rule (right reasoning) and the standard that determines it(4:VI 1 1138b34). He begins his examination by considering some observations about the soul and its two parts: a rational one and another non-rational(4:I 13). Regarding the part of the soul endowed with reason, he separates it into two parts: one that enables us to contemplate immutable things and the other that enables us to contemplate variable things, which are subject to changes. The first can be called scientific and the second calculative, since calculating and deliberating are the same, and one does not deliberate about immutable things(4:VI I 1139a5-14). According to Bobzien, this explains why the second part is responsible for deliberation, and through it, determines the means by which the ends will be achieved. Practical wisdom (*phronesis*) is the virtue of the deliberative part(12).

Practical wisdom (*phronesis*) is one of the intellectual virtues. In general terms, Aristotle considers it good deliberation, and the person endowed with practical wisdom (the *phronimos*) is the one who deliberates well. However, practical wisdom cannot be scientific knowledge and cannot be art (*techne*). First, because variations in knowledge are not allowed; second, because in art, what is in question is making and not acting. What remains, then, is that practical wisdom, with regard to actions taken for the sake of human good, is a rational quality that leads to truth, but not to immutable truths(4:VI 5), since there is another kind of wisdom, according to Aristotle. This is philosophical wisdom (*sophia*). It combines intelligence and scientific knowledge, the knowledge of the most sublime things. Practical wisdom relates to human actions and things amenable to deliberation(4:VI 7).

If practical wisdom (*phronesis*) relates to human things, then it relates to moral virtue. Aristotle considers that moral virtue is the disposition in which right rule (right reasoning) is, and practical

wisdom (*phronesis*) is right rule (right reasoning) concerning action. Thus, moral virtue is a disposition in accordance with practical wisdom (*phronesis*)(4:VI 13 1144b24-27). According to Aristotle, although practical wisdom (*phronesis*) had no practical value, “we should have needed it because it is the virtue of the part of us in question; plain too that the choice will not be right without practical wisdom any more than without virtue; for the one determines the end and the other makes us do the things that lead to the end”(4:VI 13 1145a3-5).

Another door opens to approach ADs through Aristotle’s ethical investigation. From the ingenious articulation between happiness (living well), virtues, emotions, practical wisdom, deliberation, deliberate choice, action and the moral agent, it is possible to analyse the role of emotions in ADs and their relationship in the manifestation of desires, values, and preferences of people, as well as what is in our power to deliberate about ADs.

ADs in an Aristotelian approach

The common frustration in modern philosophy with regard to Aristotle’s ethical inquiry not providing external justification of ethics, that is, its objective correctness, is clear(11). The question about such accuracy was not asked by Aristotle. Aristotle’s ethical investigation does not provide us with recourse to universal rules of action, in a robust theory of action, because, at least, a rule of action is not extracted from the controversial doctrine of the middle term (mean), even if virtue as a middle ground between two vices guides virtuous action(13). Furthermore, the origin of the action is in the agent, and it is up to him, in a way, to be the “rule” of the action. If this is correct, what can Aristotle’s ethical investigation offer to the approaches about ADs if their foundations rest on theories based on moral principles such as the principle of respect for people’s autonomy?

We intend here, in general terms, to consider the ADs, based on some of Aristotle’s claims in the *Nicomachean Ethics*(4) about feeling and acting, admitting three possible approximations: 1st) emotions and the ADs; 2nd) deliberate deliberation and choice, and ADs; 3rd) “How to lead our lives?” and the ADs.

Emotions and ADs

ADs represent the human capacity to choose and act autonomously (as self-government). Such autonomy implies, in a sense, not succumbing to inclinations, emotions, so that anticipated choices about future medical care rationally express the desires, values and preferences of the people who elaborate them. In addition, anticipated choices can reveal a certain justified security about an uncertain future without all the risks that result from facing sensitive situations about death and dying. So, what does it mean to integrate emotions closer to the ADs process?

Emotions occupy an important place in Aristotle's ethical investigation. As noted by Zingano, in the practical domain, emotions play a significant role in moral action, even though they contrast with reason. In moral action, it follows that emotional and non-cognitive elements are present. Emotions, he goes on, must be previously educated by moral habit, so that reason can give them the correct direction(16:23-4). In the same sense, Molewijk et al., consider that in Aristotle, emotions move human thought and actions, and practical wisdom is not constituted by the abandonment of emotions, but by the development of emotions adequate to the concrete situation, where the choices and actions operate(17).

With regard to emotions, what considerations are possible about ADs? One of them is the instability of the decisions expressed in ADs, one of the most common criticisms. If people's desires, values and preferences can change over time, what guarantees the ADs moral authority to be required in the future? Stability in ADs decisions is one of the criteria for their support, and the manifest expression of self-determination by people assumes that they are free and reasonable. However, what is the role of emotions in the ADs process? Would they indicate the inevitable instability of decisions? Yes, if we admit, at the origin of ADs, that the idea of rationally controlling decisions about future medical care is correct. No, 1st) if we consider the expectation of control over such care as unrealistic (perhaps it would be more effective to admit that human decisions are permeated by feeling, acting and indeterminate contexts); no, 2nd) if we admit with Bobzien that emotions are as

human as reason(12). People's desires, values, and preferences do not seem to arise exclusively from rational inquiry.

Bringing ADs closer to an Aristotelian approach here may imply their shift to the practical domain of Aristotle's ethical investigation, recognizing that emotions are part of human choices and actions. This is an unavoidable risk. The process that constitutes the elaboration of ADs involves emotions that do not weaken them but make them authentic. ADs are fixed in relation to the stability of decisions, but are always required in the indeterminacy of circumstances. When choosing in advance about future medical care, people deposit in them not only the ways of understanding life and a happy life, but also the ways of feeling and acting. Decisions in ADs do not seem to occur despite emotions, but with them.

Deliberation, deliberate choice, phronesis and ADs

What constitutes the ADs elaboration process? What kind of decisions are involved? What is in people's power to decide? The ADs express, among other things, the idea of controlling our lives, determining, when possible, which life to live and which death to die, including. Decision-making strategies in medical care are common(18). For end-of-life care, which involves ADs, such strategies serve as a guide so that decisions involving the patient, family, and health care professionals express the patient's desires, values, and preferences and cause the least possible suffering to the family and to the professionals. As previously highlighted, the intended approach here is not intended to consider such strategies, but to address the process of elaborating ADs from what is within our power to deliberate, as formulated by Aristotle.

Deliberation is an inquiry that precedes deliberate choice. In Aristotle, only things within our power, and which may be different from what they are, are subject to deliberation. Death is an end set by nature, and if it is not within our power to decide whether to die or not, then what would be left for ADs if we restrict them to end-of-life care? Perhaps just deliberating about the means by which we wish to deal with death and dying, here and now, and projected into the uncertain future. It is

an attractive idea, but it seems ineffective, because for the moral agent, the field of manoeuvre for deliberation in ADs is restricted, since it remains for us to deliberate on the means and not on the ends, in the same way that the doctor does not deliberate whether he will cure or not, but only about the means by which he will reach the established end: the health of the patient.

Thus, in relation to the process of elaborating the ADs, it seems clear that it is up to the person in this process to deliberate and choose the course of action for the future since they know the current circumstances where their manifestations about consent or refusal of future medical care rest. However, it is worth mentioning that the agent deliberates and chooses something that will happen in the future, they do not have control over the action, as it is about the control over the choice. We can consider, on the other hand, that if deliberate choices operate in contingencies, in particular circumstances, it is impossible to assume what the person would want in the situation of no longer choosing which medical care to consent to and which to refuse; they would need to be in a future situation. In this way, we deliberate and choose in ADs in view of the circumstances in which we are.

In the practical domain established, we deliberate, choose, and act, here and now, and nothing else. In this domain of uncertainties, the practical wisdom (*phronesis*) of the virtuous person (the *phronimos*) will indicate, weighing reasons, which emotions and actions are correct, taking into account what is appropriate in each situation, in what way, in relation to whom and with what end(4:II 2 1104a32;3 1104b21-24;6 1106b20-23). In a sense, it is the yardstick for good deliberation, deliberate choice, and good action(15). Roughly speaking, it is up to the person in the process of preparing an ADs to establish, in the manner of a virtuous person, 1st) whether or not to prepare the AD; 2nd) through deliberation, weighing reasons, what is the most appropriate course of action for the circumstance, in view of the desired end; 3rd) deliberate choice, deciding whether the course of action offered by the deliberation will be chosen; 4th) that the choice made will be fulfilled in the future, but still dependent on a concrete circumstance. Despite the AD be-

ing constituted in view of the uncertain future, it will always be required in the present.

Good deliberation, deliberate choice, and good action, according to Aristotle, will always depend on the pairing of moral virtues with practical wisdom (*phronesis*), as noted by Russell(19). Roughly speaking, good deliberation, deliberate choice and good action in ADs require education for virtues (morals and *phronesis*), not to learn deliberative strategies, but of learning how to live well and die well, becoming in people sensitive to circumstances and facts(19). As rational agents, Lawrence highlighted, we aim to obtain the best, and this seems to be good living. The task of reason is both to seek what correctly constitutes good living and to maintain it. Good living is expressed by the constancy of virtuous actions(13).

"How to lead our lives?" and the ADs

"How to lead our lives?" seems to encompass, in a broad sense, the human capacity to elaborate projects on which to live and carry them out through choices and actions. Although it leads us to elegant ideals for these projects, such as the perfect life or what life should be, the question that never gets old seems to be limited to the contexts of the human world. This seems to be that of the possible, the contingent, subject to the indeterminacies of the human being. Not without purpose, Aristotle considered that ethical investigation does not aim at knowledge, such as knowing what virtue is, but aims to make us good(4:II 2 1103b26-28).

The central place assigned to reason in the contemporary world, as pointed out by Thiel, prompts people to take responsibility for their lives and deaths, extending this place to the point where subjective approaches to death and dying are no longer possible(20). ADs, to a certain extent, express part of this perspective, as they create the feeling that even death can be dominated, neglecting the existence of a body, with its desires, values, and preferences. The search for mastery of the future, although far from being achieved, is a human need.

The manifestation of wills, desires, values, and preferences, through ADs, comes close to the

determination of conduct for an uncertain risk situation, in which the patient, family members, and the health team contribute to the predictions. However, the virtual reality that is planned may not be the reality that will actually be presented. Possible safety mechanisms include the adoption of precautionary measures, such as that consist of designating a well-informed legal representative (substitute decision-maker), as well as care by health care professionals who are prepared to interpret unforeseen situations, so that they can be adapted as closely as possible to the person's wishes. With this, the total control of the person's autonomy through the ADs, although it can contribute decisively to their benefit, does not fail to present clear limitations. Perhaps this is one of the challenges to the principle of individual autonomy: not neglecting concrete contexts, real people, and existing relationships.

Aristotle's ethical investigation in *Nicomachean Ethics*(4) expresses the recognition that the practical domain is a field of imprecision and, therefore, the truth is by approximation. Perhaps the possible approach to the question "how to lead our lives?" in the context of ADs is to recognize that a happy life is a long process of virtuous choices and actions, here and now, and that even in the face of their consistency, we are always subject to failure. Therefore, Aristotle insists on education for virtues from an early age. However, nothing is guaranteed. Perhaps this is one of the few possible contributions of the Aristotelian approach to ADs, considering the question "how to lead our lives?", Wiggins points out that under no circumstances can the moral agent resort to a rule to determine what to do(21). Like the archer who aims his arrow at the target, maybe we also aim at which life to live. Just as the archer is not sure if he will hit the target before shooting the arrow in its direction, we will not know how to lead our lives without the choices and actions that lead to it. The aim is a happy life and good living.

Final considerations

In a way, this is the framework in which we intend to draw lines of approximation between the Aristotelian question "how to conduct our lives?" and ADs. In this investigation, we were interested in what is involved in the question "how to lead

our lives?" in a complete life, in each choice, here and now, with human limitations, with the indeterminacy of circumstances, with the uncertainty of the future, with death and dying.

Therefore, perhaps the ambitions to control future scenarios that address ADs derive from the desire to control the practical domain in which our choices and actions operate. Perhaps, also, ADs can contribute to making the life we live complete, through the most appropriate way of consenting to or refusing future medical care, with our desires, values and preferences, in short, with our biographies, in the appropriate context, in relation to the appropriate things, in the appropriate way, in relation to the appropriate people, with the appropriate emotions, at the appropriate time. Perhaps the ADs involve decisions with deliberate choice preceded by desire, deliberation, weighing reasons, to find the most appropriate course of action and achieve the desired end, such as dying without suffering. Aristotle, agreeing with Plato, emphasizes the importance of being educated from an early age to rejoice and suffer with to appropriate things, as noted by Hursthouse(22,4:II 3 1104b13).

Thus, we conclude that the purpose of human life, according to Aristotle, is not simply to live, but to live humanly; that the answer to the question "how to lead our lives?" also involves considering death and dying; and that Aristotle's ethical investigation may be an alternative, although limited, to address ADs without the necessary appeal to moral rules.

These were the approaches considered and pursued, from an uncontroversial position of Aristotle's ethical investigation in *Nicomachean Ethics*(4): we do not deliberate well, choose deliberately and act well despite emotions, but with them.

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MARGINALIZING QUALITATIVE KNOWLEDGE: ETHICAL AND EPISTEMIC TENSIONS IN MEDICAL RESEARCH CULTURES

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Abstract: This paper examines the challenges of qualitative research in medical contexts through our position as qualitative researchers, bioethicists, and ethics committee members in Turkey. We explore how biomedical paradigm dominance shapes qualitative research evaluation in medical settings, arguing that qualitative understanding is essential to medical knowledge production, not merely a methodological choice. Through experiential insights, we identify critical issues: insufficient methodological awareness among researchers, limited recognition of qualitative paradigms by ethics committees, and persistent epistemic injustice in evaluation processes, even within traditionally receptive fields. These challenges arise from deeper philosophical tensions rather than procedural difficulties. We propose reflexivity as both a methodological requirement and an ethical virtue to address qualitative research marginalization in medicine. Our analysis contributes to discussions about the relationship between ethics and science in qualitative research while offering practical insights for improving evaluation and support of qualitative methodologies in medical contexts.

Keywords: qualitative research, bioethics, research ethics, epistemic injustice, reflexivity

Marginando el conocimiento cualitativo: tensiones éticas y epistémicas en las culturas de investigación médica

Resumen: Este artículo examina los desafíos de la investigación cualitativa en contextos médicos, desde la perspectiva de investigadores cualitativos, bioeticistas y miembros de comités de ética en Turquía. Exploramos cómo el predominio del paradigma biomédico influye en la evaluación de la investigación cualitativa en entornos médicos, argumentando que la comprensión cualitativa es esencial para la producción de conocimiento médico, no una mera elección metodológica. A través de perspectivas experienciales, identificamos problemas críticos: la insuficiente conciencia metodológica entre los investigadores, el limitado reconocimiento de los paradigmas cualitativos por parte de los comités de ética y la persistente injusticia epistémica en los procesos de evaluación, incluso en campos tradicionalmente receptivos. Estos desafíos surgen de tensiones filosóficas más profundas que de dificultades procedimentales. Proponemos la reflexividad como un requisito metodológico y una virtud ética para abordar la marginación de la investigación cualitativa en medicina. Nuestro análisis contribuye al debate sobre la relación entre la ética y la ciencia en la investigación cualitativa, a la vez que ofrece perspectivas prácticas para mejorar la evaluación y el apoyo a las metodologías cualitativas en contextos médicos.

Palabras clave: investigación cualitativa, bioética, ética de la investigación, injusticia epistémica, reflexividad

Marginalizando conhecimento qualitativo: tensões éticas e epistêmicas nas culturas de pesquisa médica

Resumo: Esse artigo examina os desafios da pesquisa qualitativa em contextos médicos, através de nossa posição como pesquisadores qualitativos, bioeticistas e membros de comitês de ética na Turquia. Nós exploramos como a dominância do paradigma biomédico molda a avaliação de pesquisa qualitativa em contextos médicos, argumentando que a compreensão qualitativa é essencial para a produção do conhecimento médico, não meramente uma escolha metodológica. Por meio de experiências pessoais, nós identificamos questões críticas: consciência metodológica insuficiente entre pesquisadores, reconhecimento limitado de paradigmas qualitativos por comitês de ética e injustiça epistêmica persistente em processos de avaliação, mesmo em campos tradicionalmente receptivos. Esses desafios surgem de tensões filosóficas profundas mais do que de dificuldades processuais. Nós propomos reflexividade tanto como um requisito metodológico como uma virtude ética para abordar a marginalização da pesquisa qualitativa em medicina. Nossa análise contribui para discussões sobre a relação entre ética e ciência em pesquisa qualitativa ao mesmo tempo em que oferece insights práticos para melhorar a avaliação e o apoio a metodologias qualitativas em contextos médicos.

Palavras chave: pesquisa qualitativa, bioética, ética em pesquisa, injustiça epistêmica, reflexividade

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Introduction

The integration of qualitative research methodologies into medical research has evolved significantly over the past decades, moving from a peripheral status to a more central position in health care knowledge production(1). Many crucial aspects of healthcare - including patient experiences, decision-making processes, and delivery systems - require approaches that capture their complexity and contextual nature(2). Qualitative research offers unique capabilities in this regard, providing insights into the human dimensions of health and illness that complement and enhance traditional biomedical approaches(3,4). However, challenges persist in the integration of qualitative methodologies in predominantly biomedical research contexts. These challenges are particularly pronounced in settings where the biomedical paradigm maintains strong institutional dominance, shaping everything from research design to ethical review processes(5). This is particularly evident in Turkey, where our position as qualitative researchers, bioethicists, and ethics committee members highlights the systemic barriers to qualitative inquiry in medical contexts.

This study examines these challenges through our unique position in the Turkish medical research environment. Our experiences align with Dwyer and Buckle's concept of the "space between" inhabiting both insider and outsider positions simultaneously, offering insights into systemic challenges facing qualitative research within institutional structures designed for biomedical research(6). This positioning reveals power dynamics and institutional frameworks that shape research practices(7). In this context, we posit that the role of a bioethicist necessitates the facilitation of dialogue and the construction of a bridge between the qualitative researcher and the ethics committees(8). Our experiences and insights into the intricacies of this relationship, both from insider and outsider perspectives, are believed to contribute valuable insights to the field.

The primary focus of this article is qualitative research; however, it is imperative to recognize that in disciplines such as medicine, where human understanding is of paramount importance, the importance of qualitative understanding goes

beyond the realm of research methodology. This claim highlights the indispensability of qualitative orientation to contexts involving concepts such as meaning and understanding. Therefore, it is insufficient to view ethical problems in qualitative research only as a matter of technical processes. When discussing the ethical dimensions of qualitative research in medicine, it is essential to consider an ethical awareness that extends beyond conventional ethical procedures, from the initiation of a research project to its publication. The contribution of qualitative understanding to medicine possesses ontological and epistemological significance, underscoring the ethical implications inherent in the subordination of these research endeavors within medical domains. In the following section, we briefly address the ontological, epistemological, and ethical dimensions of qualitative understanding (and not merely qualitative research) in medicine. We believe that this section is also fundamentally important for experiential insights and discussions.

The Ontological, Epistemological, and Ethical Meaning of Qualitative Research in Medicine

Contemporary philosophers of medicine, such as Fredrik Svenaeus, as well as great physician philosophers of the past, such as Galen, emphasize in their reflections on medicine that medicine cannot be seen simply as a reductionist application of technical (or scientific) knowledge(9,10). In this context, medicine is not merely the reduction of existing knowledge to practice but a field of understanding and action that extends beyond this(11). The humanistic aspect of medicine, which should not be reductionist, has been emphasized since Hippocrates(12). However, while the technocratic reduction of medicine's approach to the individual in the modern period is a frequently criticized issue, it has been pointed out that professionalism in medicine should be rebuilt in a humanistic sense(13–16). The definition of health by organizations such as WHO or the person-centered medicine approach, which recently emphasizes the importance of understanding the first-person experiences of patients in different contexts (diagnostic, adherence, outcomes), is also seen to contain a strong emphasis on the aspect of medicine that should not be reductionist(17–19). These findings indicate that the effort to orient patients

and understand them in the field of medicine and medical research should not be reduced to a single paradigm. As educators and researchers working in fields such as medical humanities and biomedical ethics, we can say that, at least in our country, we are appreciated for emphasizing humanistic approaches, the importance of understanding the patient holistically, and the importance of ethical approaches and philosophical perspectives within the medical climate. However, when it comes to finding a place for these as a value in practice or research, we can express that we regret to see that these are generally considered as intellectual fields of endeavor that do not go much beyond appreciation(14,16,20). We have even been exposed to discourse from some basic science fields of medicine in which this endeavor is “paramedical work”. First, we do not take offense at being exposed to such discourses, but we can express our sadness at being exposed. In this discourse, we can say that we find it ironic that the effort to understand human beings in a multidimensional way with different dimensions, which we think is inherent in medicine, is interestingly reduced to a secondary or insignificant position, not inherent to medicine. Almost parallel to this, it is possible to express regret that qualitative research is also evaluated in a secondary position within the current medical paradigm. This problem stems from an insufficient understanding of the ontological and epistemological position of qualitative research in medicine. The challenges we face as researchers, bioethicists, and ethics committee members are closely related to this gap. Before sharing our experiences, we briefly note that qualitative research has strong ontological, epistemological, and ethical justifications for medicine. In addition, when considering our endeavor in the field of medical sciences, we would like to state that we do not see quantitative or qualitative methods as the opposite or alternative of each other. These studies are important complements of a whole and sometimes express enriching ways of looking at the same thing or reality(21,22).

“What is it like, from the patient’s perspective, to suffer from illness? Answering this question is crucial to make sense of medicine as an endeavour struggling with other problems and having other aims than merely those of an ap-

plied biology.”(11)

Medicine is not only a science but also a field of action to alleviate human suffering, starting from understanding and making sense of it. We can say that understanding and making sense of pain and acting based on this constitute the basis of the ontological orientation of medicine. This makes medicine an intensely relational field(23,24). When we think about the dimensions of understanding and signification and the relational dimension of medicine, we see that these dimensions cannot be easily reduced to a quantitative dimension. Therefore, when we look from this basis, we realize that qualitative orientation (or understanding) has a fundamental ontological meaning for medicine, especially for professionals working in this field, even before we come to the issue of “formal research”. This ontological basis inevitably pushes us toward a methodology that aims to understand and make sense of things that cannot be easily reduced to quantitative data in epistemological terms. While we position qualitative orientation as having primarily ontological and epistemological meaning, this is not a dualist view that excludes the biomedical perspective. The reason for our emphasis on the ontological and epistemological meaning of qualitative orientation is that despite positive developments in qualitative research (more evident in fields such as nursing), unfortunately, it is still common in mainstream medicine to position qualitative orientation as secondary or external(1). We believe that this problem is even more prevalent in developing countries, such as Turkey. We hope that some of these reasons will be more easily understood when reading the sections on our experiences. We now briefly examine qualitative research on the dimensions of meaning and signification. Medicine is inherently too complex to be reduced to a single methodology(16). As each patient is a unique and dynamic being, there is an inevitable gap between scientific knowledge of the general and universal and the application of this knowledge to specific situations. Understanding an individual requires grasping how universal principles interact with particular situations while attending to relevant contextual details(16). In fact, whether the physician realizes it or not, he/she carries these closely related tensions in his/her identity. A medi-

cal professional is inevitably a representative of a dual identity, equipped with scientific knowledge on the one hand, but also oriented as a practitioner toward other individuals of whom they/are a member. We think that clinicians are quite aware of this in their daily practice, but when it comes to scientific studies, for some reason, the acceptance of the absoluteness of the universal or scientific still predominates(25). However, the complexity of medicine and the people it deals with make methodological pluralism a necessity for research. In this context, it is important to be aware that a complex field of social reality such as medicine cannot be made sense of only with a positivist or post-positivist approach, and it is important to be aware of approaches such as constructivism or scientific realism. In this respect, it is necessary to take into account that medicine is a field where there are different layers of reality, as some authors have stated, and research to access them can be complex in this context(22). Through a variety of approaches, the experiences and knowledge of the individual who produces meaning and lives in a wide world of meaning becomes an extremely important subject of study. Therefore, it becomes an important issue to understand the meaning produced by the individual and the impact and meaning of this meaning in the field of social reality, rather than revealing a truth that just stands there. For instance, understanding a patient's experience—especially when it does not neatly align with the biomedical paradigm—requires a distinct effort to bridge this epistemic gap. However, this does not require strictly adhering to the biomedical model, nor does it mean abandoning it altogether. Rather, an epistemically humble attitude and an awareness of different perspectives will suffice.

When we examine the ethical implications of the marginalization of qualitative research, we see that this is not only a problem of methodological choice but also an attitude with important ethical consequences. The subordination of qualitative research and participants' experiences can be seen as a fundamental problem of injustice(26). This situation prevents the voices of disadvantaged groups from being heard and damages the principles of justice and beneficence, which are the basic ethical principles of medicine. The connection between

qualitative understanding and medical ethics, as Svenaeus emphasizes, is grounded in the fact that medicine is not a purely technical practice, but a field of understanding and action that extends beyond this(9). As Bleakley emphasizes in the field of medical humanities, the endeavor to understand the human being is a fundamental goal for both medical humanities and bioethics(27). This inevitably makes qualitative research an indispensable tool of understanding and signification for these fields.

Before sharing our experiences, we would like to emphasize that qualitative research in medicine is not only a methodological choice but also a requirement of the ontological structure of medicine, epistemological pluralism, and ethical responsibility. Considering the wide scope of medicine, the fact that it includes many different disciplines together, and that it interacts with different stakeholders as an institution, it is important to be aware that different views of reality and models of knowledge production may have different meanings in terms of ethics and values. It is a fundamental requirement for qualitative research to reach the position it deserves, especially for this awareness to become established in individual researchers, research ethics committees, journal editors, and academic institutions.

Experiential Insights from Inside and Outside

Being a bioethicist in the field of medicine offers us the experience of being in different positions. Participating in educational activities, including research and publication ethics, conducting scientific research, and serving on different ethics committees, depending on the nature of our field, are the main activities. In this context, we think it would be appropriate to present our experiences under headings related to our experiences in these fields of study. We would like to state that all these experiences have ontological, epistemological, and important ethical meanings. Key findings from our experiences include: weak methodological awareness among qualitative researchers; limited recognition of qualitative paradigms by ethics committees; positivist influences in evaluations; researchers' reluctance to defend their methodologies; and epistemic injustice in publication processes, even within traditionally receptive fields.

Problems before the ethics committee or the unbearable lightness of being a qualitative researcher!

As qualitatively oriented bioethicists, we've observed that qualitative research faces serious theoretical and practical problems. Despite its importance for understanding patients' experiences, qualitative research remains peripheral in medical curricula, often reduced to merely a title in statistics-dominated research courses. We observed that such courses are generally conducted by instructors with a statistical or quantitative orientation. All of these seem to implicitly relegate the visibility and importance of qualitative research to a secondary position. It is possible to state that a similar problem exists at the postgraduate level. Based on our experience—working in one of the most established medical schools in Turkey—qualitative research methodology remains insufficiently integrated into medical education, except in disciplines that have a relatively strong orientation toward the social dimensions of health. For instance, in our unit, a course on qualitative research methodology was introduced in 2023. However, bioethics remains the only well-established discipline within medicine in Turkey that primarily focuses on meaning and understanding, similar to the human sciences in medicine. One of the authors of this article taught this course, and his experience highlighted the inadequacy of qualitative research training in medical and health sciences curricula. Unsurprisingly, almost all postgraduate students in our courses—primarily from health sciences backgrounds—were unfamiliar with qualitative methodology. Furthermore, certain key concepts in qualitative research proved challenging for students to grasp. The primary obstacle was the pervasive influence of the established biomedical and statistical paradigm, which required continuous reminders to reorient students' perspectives. Even now, we encounter difficulties stemming from the entrenched statistical ethos when guiding students through qualitative research.

We are pleased to see a growing interest in qualitative research in Turkey as well as globally. This is evident in the increasing number of publications in the field. However, as mentioned earlier, the increase in publications on a methodology that is still insufficiently integrated into curricula has

important epistemological and ethical implications that warrant discussion. Our concern stems from observations and experiences in collaborative research with educators and other researchers. One key issue is that some individuals, perceiving themselves as insufficiently proficient in statistics or mathematics, view qualitative research as an easier alternative. To some extent, this reflects a misuse of qualitative research's ontological and epistemological foundations—particularly its focus on life experiences and the subjective worlds of research participants. Given the ontological, epistemological, and ethical significance of qualitative research, we consider this a serious ethical concern. This issue becomes even more critical when we recognize the substantial contributions and ongoing discussions surrounding qualitative research quality. When we ask a researcher conducting qualitative research why they chose this methodology, we often receive responses such as, "I don't know statistics, so at least I can do this [qualitative research]." Unfortunately, when we inquire whether they have received formal training in qualitative research, we frequently struggle to receive an affirmative answer.

This experience highlights two key issues. First, statistical data remains the dominant and more prestigious form of evidence, particularly in medicine and health sciences. While we do not argue that statistical methods lack value, qualitative research continues to be perceived as secondary and is often not treated as a field requiring rigorous training. This, in turn, raises concerns about both the quality of qualitative research and the competence of researchers engaging in it. From our perspective, this situation makes scientific competence—one of the fundamental requirements of research ethics—both questionable and problematic from the outset. However, we also want to emphasize that our critique is not intended to unfairly target academic units or educators providing qualitative research training. Nevertheless, when we compare the training we receive in Turkey, particularly in the health sciences, with the training available in countries where qualitative research is more established, we must acknowledge that qualitative education in Turkey tends to maintain a discourse that is ontologically and epistemologically closer to the post-positivist end

of the spectrum. In this respect, it is possible to state that qualitative research is not addressed comprehensively within the spectrum of small q-big Q, and that the ontological, epistemological philosophical framework toward the end close to the big Q concept or interpretation is not sufficiently established(28). This may be significantly related to the dominant paradigmatic view in the field of health sciences(29). In conclusion, we would like to add that the ontological, epistemological, and ethical meaning of qualitative research in medicine has not been sufficiently discussed at the theoretical and philosophical levels. However, in fields such as medicine, where researchers from different disciplines and paradigms come together, it is important to be familiar with both our own paradigm and the approaches of the researchers we work with, even at a basic level (30)from psychology to engineering to rhetoric. Trained in these traditions, HPE researchers engage in science and the building of new knowledge from different paradigmatic orientations. Collaborating across these traditions is particularly generative, a phenomenon the authors call the multidisciplinary edge effect . However, to harness this productivity, scholars need to understand their own paradigms and those of others so that collaboration can flourish. This Invited Commentary introduces the Philosophy of Science series—a collection of articles that introduce readers to 7 different paradigms that are frequently used in HPE research or that the authors suggest will be increasingly common in future studies. Each article in the collection presents a concise and accessible description of the main principles of a paradigm so that researchers can quickly grasp how these traditions differ from each other. In this introductory article, the authors define and illustrate key terms that are essential to understanding these traditions (i.e., paradigm, ontology, epistemology, methodology, and axiology. Yes, if we look at the field of health sciences in Turkey from a purely quantitative and practical perspective, we can say that a significant number of qualitative studies are being conducted. However, we observe that issues such as the meaning, foundations and value of qualitative research in different medical contexts - such as education, understanding experiences and clinical outcomes - have not been adequately addressed. In this regard, we would like to emphasize that

existing training programs, where they exist, are largely limited to the practical aspects of conducting and publishing research, rather than encouraging a deeper engagement with its theoretical and methodological dimensions.

The predominantly negative experiential content discussed in this section is closely linked to the themes explored in the following two sections. While it is not our intention to suggest that every researcher must become a methodological expert, we believe that the lack of awareness regarding even basic concepts and the distinctive epistemological characteristics of qualitative research represents a significant issue in Turkey. This gap in understanding is directly connected to challenges encountered in research ethics committees and publication processes, which will be discussed later. However, this issue is not confined to Turkey; similar challenges can be observed in the publication process globally, including during editorial and peer-review evaluations. Moreover, as researchers who have lived these processes may eventually serve on research ethics committees, become journal editors, or act as reviewers, the medical field needs to cultivate researchers and students who possess a solid grasp of their discipline and are well-acquainted with diverse methodological approaches(30,31).

Insights from inside the ethics committee: There was a lack of methodological awareness and relevant problems

Our experiences as both ethics committee members and applicants reveal that qualitative research applications in medicine are extremely limited compared to quantitative research and confined to certain fields. In addition, regarding qualitative and quantitative research categories, it is possible to say that research ethics committees treat many survey research that actually have a qualitative character as classical quantitative research. We believe that this situation is closely related to the established biomedical and statistical research paradigm. Although limited, qualitative research applications are also affected by this paradigmatic influence in various ways.

Reflecting on our applications, qualitative research either receives cursory approval or faces

quantitatively driven critiques that force conformity to biomedical and statistical discourse. Both tendencies, we argue, present ethical concerns. The root of this issue lies in the composition of research ethics committees, which are predominantly oriented toward biomedical and statistical paradigms. Even when committee members possess some familiarity with qualitative research, they often evaluate it through a quantitative lens. As a result, ethical evaluations tend to emphasize concepts such as sampling, validity, and reliability—aligning with the expectations of statistics-based biomedical models. However, despite this methodological emphasis, the ethical dimensions of qualitative research and the researcher's relationship with participants remain relatively underexplored. In other words, prioritizing statistically driven evaluations can lead to formalistic and mechanistic assessments that overlook other ethically significant aspects. To some extent, this also contributes to the tendency for ethics committees to grant easy approval to qualitative research that is framed within a quantitative paradigm.

These problems largely stem from an insufficient understanding of qualitative research and its significance within medicine. The ontological, epistemological, and ethical dimensions of qualitative research remain poorly understood by researchers and ethics committee members alike. Two key situations illustrate this issue. First, based on our experience with ethics committees and research applications, we have noticed that researchers and ethics committee members from various health sciences disciplines often fail to situate qualitative research within a broad paradigmatic continuum. In practice, even when an ethics committee member claims to have a qualitative orientation, they frequently evaluate qualitative research as a singular methodological approach rather than recognizing its diverse paradigmatic orientations. Consequently, assessments, suggestions, and critiques tend to align predominantly with a post-positivist (small q) perspective. Second, this issue may also be influenced by ethics committee standards and review protocols. For instance, in nearly all of the ethics committees we have worked with or applied to, researchers are required to numerically declare their sample size in application forms. Such formal requirements may contribute to reinforcing

a post-positivist framing of qualitative research. More broadly, the role of standardization, checklists, and guidelines in qualitative research remains a topic of ongoing debate worldwide(32). In this context, we can say that research ethics committees need guidelines that take qualitative research methodology into account and define it in detail instead of quantitative and statistically oriented application standards. This may provide an opportunity not only for ethics committee members and researchers to reflect on the nature of their research. In this context, it is essential to take into account the pluralistic orientation of qualitative research, which is not absolutist and allows flexibility, which some researchers rightly and persistently emphasize, in order not to fall into a new reductionism(32).

In the previous section, we highlighted that the awareness and competence of individuals conducting qualitative research regarding the nature of their work constitute a distinct problem category. We observe a clear reflection of this issue within research ethics committees. Researchers must demonstrate methodological congruence; in other words, they should have a clear understanding of what they are doing and writing(29). Unfortunately, one of the challenges we encounter as ethics committee members is that when researchers receive feedback or negative criticism from the committee, they often struggle to defend their methodological position adequately. Even when we believe they are justified in their approach, they frequently remain passive in their responses. One possible reason for this is the perceived dominance of the quantitatively oriented biomedical paradigm, which may leave researchers feeling powerless in challenging the prevailing standards. However, in our view, another key issue is that many researchers have yet to reach what Braun and Clarke describe as the “knowing researcher” stage—a critical level of methodological competence(31). Additionally, it is not uncommon for researchers to adapt their approach to align with small q qualitative research or even quantitative methodologies due to the pressures of the “publish or perish” culture(33). This tendency to conform further entrenches the statistically oriented paradigm and reinforces existing ethics committee review processes. We argue that when researchers

develop a stronger understanding of their methodology and confidently articulate their position, they may also encourage research ethics committees to critically reflect on their own evaluative frameworks(34-36).

Across all scientific disciplines in Turkey, the establishment of research ethics committees has been primarily shaped by legal regulations in the health sciences. Although regulatory changes in this field are frequent, legally binding clinical research ethics committees inevitably serve as a model when determining the principles for other ethics committees. We highlight this point because clinical research ethics committees operate within a predominantly biomedical and statistically oriented framework(37).

However, the role of research ethics committees extends beyond merely evaluating research protocols for approval. They also play a crucial role in promoting education, providing guidance, and shaping policies on research and publication ethics. Studies indicate that persistent challenges in this area suggest the need for research ethics committees to critically reassess their training, advisory functions, and policy development processes. In our view, it is essential for research ethics committees to adopt a comprehensive evaluative framework that considers the broader implications of their decisions. This requires committee members to develop the expertise necessary to engage with diverse research methodologies, contribute to their advancement, and intervene when necessary. Given the complexity of human understanding—an aspect that cannot be reduced to purely biological applications—we argue that research ethics committees should approach qualitative methodologies with a perspective that is both virtuous and flexible, prioritizing the depth of human experience in their assessments(3,9,14).

A disappointment: Epistemic injustice against qualitative research and the researcher; even in the field of bioethics

In the field of medicine, qualitative research continues to face challenges in gaining recognition, as many medical journals still do not prioritize it. Even when qualitative studies are included in the review processes of medical journals, they are

frequently evaluated through a quantitative or post-positivist lens (32). Consequently, the experiences we discuss here will likely resonate with many qualitative researchers. As scholars engaged in both qualitative research and research ethics, we frequently encounter similar challenges. However, we believe that the core of our argument lies in the unique role of qualitative research in fostering an understanding of human experiences. Even in disciplines familiar with qualitative methods, a lack of reflexivity still poses challenges for researchers.

Bioethics, a field in which we conduct academic studies, shares a close relationship with medical humanities. The pursuit of understanding human beings is a fundamental aim of both disciplines, making qualitative research an indispensable tool for exploring and interpreting these fields(27). Although bioethics and ethics are often considered more theoretically driven disciplines, there has been a growing emphasis on empirical studies, particularly in bioethics. This shift has allowed for deeper exploration of individuals' values, decision-making processes, lived experiences, and their ethical and normative dimensions(38). Some scholars have even referred to this trend as the “empirical turn” in bioethics(39,40). Given the nature of bioethics, qualitative research constitutes a significant portion of empirical studies in the field(41). In this context, it is reasonable to expect that journals specializing in bioethics and medical humanities would be well-versed in evaluating qualitative research. However, as we will discuss further, epistemic injustices against qualitative research and researchers persist even within these disciplines, raising important concerns about the way qualitative methodologies are assessed and valued.

However, as the title of this section suggests, we regret to acknowledge that even in leading journals in the field of bioethics and medical ethics, qualitative research articles are not uncommonly rejected based on post-positivist criteria during editorial and peer-review processes. To illustrate this, we would like to briefly share a recent experience with one of our articles that centered on “participant experiences”—ironically focusing on research ethics. We believe this case serves as a valuable example for understanding the epistemic position of qualitative research and its researchers. Our article was evaluated by two reviewers.

One reviewer demonstrated a strong command of qualitative methodology, offering feedback and critiques that aligned with qualitative research principles. The second reviewer, however, approached the article from a distinctly post-positivist stance, raising concerns about generalizability and sampling that demonstrated a misunderstanding of qualitative research principles, including purposive sampling. While we could have addressed these critiques by clarifying the nuances of our methodology, we were denied the opportunity to do so. So, what happened? The editor rejected the article outright based on the quantitatively oriented reviewer's concerns, despite the qualitative-familiar reviewer recommending only revisions. The editor deemed the paper 'unfixable' due to supposed scientific method deficiencies. What makes this case particularly striking is that it took place in a well-regarded journal in the field of bioethics and medical ethics—a field where qualitative methodologies should, in principle, be recognized as essential. Following this decision, we mailed the journal to express our concerns regarding the editorial and review process, highlighting the established role of qualitative research in bioethics and the ethical implications of dismissing qualitative methodologies based on positivist paradigms. Our motivation for doing so was our deep concern that qualitative research was being constrained by entrenched epistemological barriers, even within an ethics journal. We argue that this is not only a methodological issue but also an ethical one. These obstacles reflect a reductionist perspective that risks dismissing the lived experiences of research participants—an issue that extends beyond individual editorial decisions and speaks to broader systemic biases. Even in disciplines like bioethics, where understanding human experience is a fundamental aim, reductionist tendencies can reemerge if not actively resisted (32). Furthermore, we argue that this reductionism represents a clear case of epistemic injustice against qualitative research and its participants. On one hand, our qualitative methodology was treated as subordinate to positivist approaches—an instance of hermeneutical injustice (26). On the other hand, we were denied the opportunity to defend our methodological choices, constituting testimonial injustice. As Fricker correctly emphasizes, epistemic injustice is a pervasive issue across differ-

ent disciplines, and at its core, it is an ethical problem. Overcoming such injustice requires not only intellectual and ethical virtues on an individual level but also a concerted effort to challenge and reform entrenched institutional biases(26).

At this point, it is essential to cultivate reflexivity regarding the ways in which the dominant positivist and post-positivist orientation in academia—especially in research ethics committees, editorial boards, and peer review—may inadvertently disadvantage qualitative research. In this context, we argue that reflexivity serves as both an ethically and intellectually meaningful starting point, functioning as a virtue that can help address issues such as epistemic injustice. Moreover, reflexivity can also be seen as a crucial tool for researchers to identify and develop their competencies in areas where they may lack expertise. Developing a deeper philosophical understanding of one's field, as well as the interdisciplinary areas it interacts with, is essential for fostering more informed and equitable evaluations(30).

Another concept closely linked to reflexivity and worth considering in this discussion is epistemic humility. Epistemic humility entails an awareness that our engagement with knowledge and methodology is inherently fallible, and that we must remain open to the possibility of error(42). By embracing epistemic humility, scholars, ethics committee members, and reviewers can foster a more inclusive and reflective approach to diverse research methodologies, ultimately contributing to a more just and balanced academic landscape.

Know thyself! Reflexivity as an ethical virtue

Our experiences highlight how ethics in qualitative research extends beyond procedural compliance with ethics committees, challenging principle-based approaches in favor of more nuanced ethical engagement(43). We propose reflexivity—a practice central to qualitative research—should be recognized as an ethical virtue embodying the philosophical imperative: "Know thyself!" This concept is particularly relevant because, in our experience, a lack of reflexivity—ranging from individual researchers to institutional bodies such as journals and ethics committees—constitutes the most fundamental barrier to mutual under-

standing and intellectual development. We argue that this deficiency is a key inhibitor of epistemic openness and progress.

A qualitative researcher's awareness of their own ontological and epistemological position carries ethical implications and consequences. Thus, cultivating philosophical self-awareness among qualitative researchers is crucial. The first step in this process is foundational knowledge of qualitative research and its underlying principles—an issue we have identified as a major obstacle. This gap in understanding must be addressed to enable epistemological reflection, which, in turn, allows for deeper reflexivity throughout the research process. Therefore, it is imperative to embed qualitative research within the intellectual frameworks of scholars in medicine and health sciences, ensuring that its ontological and epistemological significance is properly acknowledged(21,30).

Reflexivity should also be emphasized as an ethical virtue for those in evaluative positions—ethics committee members, editors, and reviewers—both at an institutional level and as individuals. Some scholars have underscored the importance of collective reflection, particularly in research groups composed of multiple researchers(44). We believe that this need for collective reflexivity extends to research ethics committees, which are expected to integrate diverse disciplinary perspectives and facilitate comprehensive epistemological evaluations. However, based on our experiences, we observe that biomedical and statistical paradigms continue to dominate these evaluative structures—either explicitly or implicitly—rather than fostering an environment that encourages critical reflection. Discourses emphasizing intellectual reflexivity must become embedded within the philosophical foundations and operational practices of research ethics committees.

We contend that fostering reflexivity in evaluative structures could promote greater epistemic equality, granting qualitative researchers a stronger voice when engaging with research ethics committees, editors, and reviewers. However, for research ethics committees and editorial boards to engage meaningfully in reflection, they must possess an informed understanding of diverse research paradigms. In fact, this expectation should be consid-

ered an essential virtue for those in positions of evaluative authority(45). Our experience suggests that these virtues must be actively and repeatedly reinforced. In this regard, we argue that a reflexive attitude serves as an essential and continuous ethical reminder for all those involved in the academic evaluation process.

Conclusion

Our experiences have revealed systemic challenges in the recognition and evaluation of qualitative research within medical contexts. These challenges reflect deeper ontological, epistemological, and ethical tensions within contemporary medical research culture. Our analysis highlights how the marginalization of qualitative research represents not merely a methodological preference but rather an epistemic injustice that has significant implications for medical knowledge production and practice.

The experiences shared in this paper demonstrate that even in fields traditionally receptive to qualitative approaches, such as bioethics and medical humanities, researchers face persistent barriers rooted in positivist and post-positivist paradigms. This situation is particularly concerning in the Turkish context, where qualitative research education remains limited and research ethics committees often operate with evaluation frameworks better suited to quantitative methodologies. The irony of experiencing epistemic injustice in bioethics journals—a field that should be particularly attuned to issues of justice and understanding human experience—underlines the pervasive nature of these challenges.

Our analysis suggests that several critical areas require attention. First, there is an urgent need to strengthen qualitative research education within medical curricula to ensure that researchers develop not only methodological skills but also a deeper understanding of qualitative research's philosophical foundations. Second, research ethics committees should develop more nuanced evaluation frameworks that recognize the distinct characteristics and value of qualitative methodologies. Third, the academic publishing ecosystem must become more reflexive about its own biases and inclusive of diverse methodological approaches.

The field of medicine continues to grapple with the complexities of human health and illness, and the need for diverse methodologies has become increasingly clear. Our experience suggests that resolving the tensions between ethics and science in qualitative research requires not only procedural changes but also a fundamental shift in how we conceptualize and value different forms of knowledge in medicine. Only through such transformation can we hope to develop a more inclusive and ethical research environment that serves both the scientific and humanistic aims of medicine.

We propose reflexivity as both a methodological requirement and ethical virtue that can help address these challenges. This approach requires all stakeholders—researchers, ethics committee

members, and journal editors—to critically examine their own philosophical assumptions and biases. In medicine, where understanding human experience is crucial for effective care, the ability to move between different paradigms and appreciate diverse forms of knowledge production is essential.

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DILEMAS ÉTICOS Y DESAFÍOS EN LA SOCIEDAD DIGITAL: UN ENFOQUE MULTIDISCIPLINARIO SOBRE LA CIBERADICCIÓN Y LA REGULACIÓN TECNOLÓGICA

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Resumen: Este manuscrito examina la complejidad creciente de la ciberadicción, un fenómeno cada vez más normalizado socialmente pero aun insuficientemente investigado y regulado. La ciberadicción comparte rasgos con otras formas de dependencia, al surgir de experiencias de placer inmediato que pueden transformarse en necesidad. Desde una perspectiva multidisciplinaria, el texto analiza factores históricos, familiares, neurobiológicos y sociotécnicos que contribuyen a su desarrollo, destacando el papel del placer digital y de las arquitecturas tecnológicas diseñadas para captar y retener la atención del usuario. Asimismo, se abordan los dilemas éticos asociados a su conceptualización, interrogando si la ciberadicción constituye un trastorno autónomo o una manifestación de transformaciones más amplias en la relación humana con la tecnología. El manuscrito profundiza en tensiones vinculadas a autonomía, vulnerabilidad, responsabilidad corporativa y privacidad, proponiendo un enfoque que reconoce la complejidad moral del ecosistema digital contemporáneo. En conjunto, el trabajo articula aportes de la neurociencia, la psicología, la bioética y los estudios sociotécnicos para ofrecer una comprensión integrada del fenómeno. Se plantea la necesidad de equilibrar los beneficios del uso intensivo de tecnologías con los riesgos asociados, promoviendo prácticas que favorezcan un uso saludable, crítico y éticamente responsable. En síntesis, se sitúa la ciberadicción como un desafío emergente de la era digital.

Palabras clave: ciberadicción, dilemas éticos, autonomía digital, regulación tecnológica, dependencia tecnológica

Ethical dilemmas and challenges in digital society: a multidisciplinary approach to cyberaddiction and technological regulation

Abstract: This manuscript examines the growing complexity of cyberaddiction, a phenomenon that is becoming increasingly socially normalized but still insufficiently researched and regulated. Cyberaddiction shares traits with other forms of dependency, arising from experiences of immediate pleasure that can become a necessity. From a multidisciplinary perspective, the text analyzes historical, familial, neurobiological, and sociotechnical factors that contribute to its development, highlighting the role of digital pleasure and technological architectures designed to capture and retain the user's attention. It also addresses the ethical dilemmas associated with its conceptualization, questioning whether cyberaddiction constitutes an autonomous disorder or a manifestation of broader transformations in the human relationship with technology. The manuscript delves into tensions related to autonomy, vulnerability, corporate responsibility, and privacy, proposing an approach that recognizes the moral complexity of the contemporary digital ecosystem. Overall, the work brings together contributions from neuroscience, psychology, bioethics, and socio-technical studies to offer an integrated understanding of the phenomenon. It raises the need to balance the benefits of intensive use of technologies with the associated risks, promoting practices that favor healthy, critical, and ethically responsible use. In summary, cyber addiction is positioned as an emerging challenge of the digital age.

Keywords: cyberaddiction, ethical dilemmas, digital autonomy, technological regulation, technological dependence

Dilemas éticos e desafios na sociedade digital: um enfoque multidisciplinar sobre a dependência digital e a regulação tecnológica

Resumo: Esse manuscrito aborda a crescente complexidade da dependência digital, um fenômeno que compartilha características com outras formas de dependência, derivada de um prazer imediato que se transforma em necessidade. Através de uma perspectiva multidisciplinar, o texto explora fatores históricos, familiares e neurológicos que contribuem para este fenômeno, destacando o papel central do prazer digital. Além disso, levanta dilemas éticos ao debater se a dependência digital deve ser considerada um transtorno em si mesma ou uma manifestação de uma mudança humana. O presente trabalho amplia essa discussão ao incorporar uma articulação mais explícita entre neurociência, psicologia, bioética e estudos sociotécnicos, permitindo compreender a dependência digital como um fenômeno emergente próprio de uma ecologia digital desenhada para captar e reter a atenção do usuário. Além disso, aprofunda-se nas tensões éticas vinculadas a autonomia, vulnerabilidade, responsabilidade corporativa e privacidade, superando o uso generalizado e impreciso do conceito "dilema" e adotando um enfoque analítico que reconhece a complexidade moral do ecossistema digital contemporâneo. É proposta uma abordagem integradora orientada a equilibrar os benefícios e riscos do uso intensivo de tecnologias, promovendo práticas que favorecem um uso saudável e eticamente responsável.

Palavras chave: dependência digital, dilemas éticos, autonomia digital, regulação tecnológica, dependência tecnológica

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Introducción

Este manuscrito surge de una reflexión multidisciplinaria orientada a problematizar la creciente complejidad de la ciberadicción, con el propósito de dialogar, deconstruir y reconstruir los conocimientos existentes sobre este fenómeno. Aunque su presencia es cada vez más visible, continúa siendo escasamente abordada tanto en la investigación como en la formulación de políticas públicas. En este marco, se vuelve necesario avanzar hacia un enfoque sistémico que articule perspectivas conceptuales capaces de superar aproximaciones fragmentadas o meramente descriptivas.

Actualmente, la ciberadicción se configura como una de las formas de dependencia más normalizadas socialmente. Su presencia es ubicua y, lejos de ser cuestionada, suele ser promovida en entornos familiares, educativos y en eventos de alcance nacional e internacional. Esta naturalización dificulta la identificación de riesgos y la implementación de estrategias preventivas y terapéuticas. La hiperconectividad, la economía de la atención y el diseño persuasivo de las plataformas conforman un ecosistema sociotécnico que estructura la vida cotidiana.

Desde una perspectiva multidisciplinaria, este estudio examina la ciberadicción a partir de conceptos clave que permiten profundizar en su comprensión y, a la vez, orientar propuestas para el ámbito de las políticas públicas. La multidisciplinarietà no se limita a la coexistencia de enfoques, sino que exige integrar neurociencia, psicología, bioética y estudios sociotécnicos para explicar tanto los mecanismos de compulsión como los condicionamientos culturales y normativos que moldean el comportamiento.

Toda adicción tiene su origen en un apego, un afecto o un hábito que puede transformarse en dependencia. Según la Real Academia Española(1), el apego se entiende como una inclinación hacia alguien o algo, vinculada a términos como afecto, aprecio o interés. En el contexto digital, estos vínculos se canalizan hacia dispositivos y plataformas que median la experiencia humana, configurando nuevas formas de apego tecnológico.

La formación de apegos implica experiencias físicas y emocionales asociadas al placer generado por una

actividad o conducta. Esta asociación refuerza la repetición y, en determinados contextos, puede derivar en un proceso adictivo. En el ámbito digital, este proceso se intensifica debido a refuerzos inmediatos y adaptativos, orientados algorítmicamente a maximizar la repetición de la conducta.

Mate(2) señala que el apego es un impulso instintivo destinado para preservar la cercanía con otros, fundamental para el desarrollo humano. A partir de esta definición, la ciberadicción puede entenderse como un fenómeno complejo influido por factores históricos, familiares, físicos y neurológicos que predisponen a la formación de apegos hacia situaciones, comportamientos u objetos, como ocurre con las tecnologías digitales. La accesibilidad permanente y la gratificación inmediata facilitan la transición desde el uso recreativo hacia patrones compulsivos.

Este apego atraviesa generaciones y contextos socioeconómicos. Para que evolucione hacia una adicción, debe existir un entorno que genere placer y bienestar difícil de encontrar fuera del circuito digital, reforzando la dependencia. Así, la ciberadicción emerge de la interacción entre predisposiciones individuales y arquitecturas tecnológicas diseñadas para estimular conductas repetitivas.

El manuscrito reflexiona sobre la transición del apego hacia la adicción, momento en que el vínculo se convierte en un trastorno que afecta a la persona y su entorno. En este contexto, se examina el rol de la ética, la bioética y la moral, así como la necesidad de analizar perfiles socio epidemiológicos y posibles tratamientos a nivel micro y macro.

El placer constituye un elemento central en esta transición. Se trata de una experiencia compleja, influida por factores biológicos y psicológicos, asociada a la activación de los circuitos mesocorticolímbicos y a la liberación de neurotransmisores como dopamina y endorfina(3). Estas dinámicas permiten explicar cómo la interacción con dispositivos digitales reproduce patrones de refuerzo propios de las adicciones conductuales.

Aunque el impulso hacia la satisfacción cumple funciones adaptativas, también puede extenderse a actividades complejas, generando dependencia. En entornos digitales, estas dinámicas se intensifican

por la inmediatez del refuerzo y la disponibilidad permanente de estímulos. Como señala Valdebenito-Herrera(4), el ser humano busca satisfacer necesidades básicas antes de desarrollar estructuras cognitivas avanzadas, lo que explica la centralidad del placer en la vida cotidiana.

El placer también opera en contextos emocionales y sociales, contribuyendo a la regulación afectiva. Incluso experiencias negativas, como la tristeza evocada por la música, pueden generar placer si favorecen la gestión emocional(5). Sin embargo, cuando se asocia a conductas adictivas, afecta la capacidad de autocontrol y la flexibilidad mental(6). En este sentido, la ciberadicción puede entenderse como una expresión contemporánea de sistemas de recompensa modulados por arquitecturas digitales altamente personalizadas.

A pesar de los avances en salud y de los Objetivos de Desarrollo Sostenible(7), la promoción del placer no ha sido considerada una estrategia preventiva. Los marcos regulatorios privilegian prácticas saludables estructuradas, sin reconocer que el placer mediado tecnológicamente puede convertirse en una vía crítica hacia la compulsión.

Este manuscrito también aborda el concepto de *trouble-disorder*(8), que distingue entre problema y trastorno, desplazando el foco desde lo social hacia la experiencia individual. En el ámbito digital, esta distinción permite reconocer que ciertos usos problemáticos no derivan de disfunciones previas, sino de la interacción prolongada con sistemas diseñados para promover la permanencia del usuario.

Siguiendo a Jaremka et al.(9), *trouble* abarca dificultades que afectan a individuos y grupos en distintos contextos, incluyendo el estrés, la ansiedad y la depresión. En la ciberadicción, estas manifestaciones pueden estar mediadas por la exposición constante a estímulos digitales y la sobrecarga informativa.

Desde la filosofía social, Butler(10,11) amplía el concepto de *trouble* al cuestionar normas tradicionales, otorgándole un valor liberador. Trasladado al ámbito tecnológico, este enfoque permite examinar cómo las prácticas digitales reconfiguran la agencia, la socialización y el consumo, generando oportunidades y vulnerabilidades.

En neurociencia, *trouble* también refiere a dificultades asociadas a trastornos cerebrales, como en el autismo, donde alteraciones sensoriales y motoras afectan la interacción social(12). Integrar esta perspectiva evidencia que las respuestas neurobiológicas al entorno digital varían entre individuos, generando niveles diferenciados de vulnerabilidad.

Desde una perspectiva neurofisiológica, la adicción es un proceso que evoluciona hacia la compulsión, influido por aprendizajes pavlovianos e instrumentales. Este proceso implica un desplazamiento del control neuronal desde la corteza prefrontal hacia el cuerpo estriado, acompañado de neuroplasticidad asociada al consumo crónico(13). La adicción puede entenderse como un ciclo de disregulación de los sistemas de recompensa, generando un estado alostático caracterizado por alteraciones crónicas(14). Diversas teorías abordan las respuestas hedónicas, el aprendizaje aberrante y el control de impulsos(15).

La impulsividad se vincula estrechamente con la vulnerabilidad a la adicción(16). La neuroplasticidad en el circuito corticoestriatal desempeña un papel crucial, ya que el consumo crónico interfiere con el control prefrontal(17). Los recuerdos inducidos por drogas pueden contribuir a la recaída al manipular la plasticidad sináptica, mientras que la exposición prolongada altera irreversiblemente los circuitos motivacionales(18,19). Los sistemas cerebrales del estrés, como el factor liberador de corticotropina (CRF) y la noradrenalina, también son fundamentales en la dependencia(20).

Mate(2) subraya que comprender la adicción requiere preguntarse qué alivio busca el adicto. La experiencia literaria de Thomas De Quincey ilustra cómo las drogas pueden ofrecer una sensación de claridad y alivio emocional. Desde esta perspectiva, la adicción surge en un terreno propicio marcado por el dolor emocional y la necesidad de evitar el vacío mental(2).

En la adicción tecnológica, el flujo constante de datos elimina los vacíos y transforma la información en conocimiento(21), aunque rara vez en entendimiento o sabiduría. Este manuscrito invita a reflexionar sobre este *trouble-disorder* en el contexto digital contemporáneo.

Dilemas éticos en la ciberadicción

La ciberadicción se define como una dependencia patológica del uso del ciberespacio y las tecnologías digitales, considerada una adicción no química con características propias en términos de nosología, etiología y patogénesis, lo que demanda prevención, tratamiento y corrección psicológica(22). Esta adicción se manifiesta en diversas formas, como la adicción a Internet, los videojuegos, el uso excesivo de gadgets, la ciber comunicación y el cibersexo(23). Investigaciones han mostrado que la ciberadicción comparte factores de riesgo con otras adicciones conductuales y puede estar vinculada con comportamientos problemáticos, como la agresión cibernética y la violencia en el ámbito digital(24,25). Además, se ha identificado como un factor de vulnerabilidad en adolescentes para ser víctimas de ciberacoso, especialmente cuando existe una falta de apoyo familiar y social(26).

En este contexto, uno de los dilemas abordados en este trabajo es si la ciberadicción debe considerarse un *trouble-disorder* o trastorno. De ser así, ¿debería ser identificada, cuantificada y tratada de manera adecuada? Al revisar la definición de problema, las actividades o comportamientos considerados trastornos suelen definirse como tal porque impiden el desarrollo pleno de la vida individual y colectiva. Sin embargo, en el caso de la ciberadicción, y más aún en el contexto económico, político y bélico actual, esa adicción no parece obstaculizar la funcionalidad ni el desarrollo personal. Por el contrario, la ciberadicción puede apoyar al ser humano al satisfacer sus inquietudes, responder a preguntas y brindar afecto a través de palabras y consejos, y ciertamente fomenta una mayor capacidad de desempeño. En consecuencia, cabe preguntarse si la ciberadicción debe ser identificada, diagnosticada, pronosticada y tratada.

Otro dilema que surge de esta reflexión es la naturaleza de los seres humanos, es decir, ¿qué tipo de *Homo sapiens sapiens*(4) somos o si estamos en un proceso de involución hacia un *Homo habilis*, en el que la rápida adquisición de información ya no constituye un desafío, sino el saber utilizar y manejar de manera hábil las herramientas tecnológicas?

A pesar de la relevancia de estos cuestionamientos, la definición de ciberadicción sigue siendo un tema

controvertido. Algunos autores la equiparan con adicciones conductuales como la ludopatía(27), mientras que otros sostienen que el uso excesivo de tecnología no necesariamente sigue los mismos patrones de los trastornos relacionados con sustancias(28). Esta falta de consenso se refleja en los criterios heterogéneos para determinar qué comportamientos son patológicos, así como en la ausencia de un diagnóstico consolidado en el DSM-5, que solo menciona de manera provisional el *Internet Gaming Disorder*(29).

El debate también abarca la cuestión de si la ciberadicción es un trastorno en sí misma o si simplemente es una manifestación de otros problemas subyacentes, como déficits de autocontrol o condiciones psicosociales adversas(30). Desde una perspectiva ética, esta indefinición plantea dilemas sobre el riesgo de sobrediagnóstico y estigmatización, o, por el contrario, de subestimación de problemas reales que afectan a personas vulnerables(31).

Uno de los dilemas más relevantes en el tratamiento de la ciberadicción es el equilibrio entre la autonomía individual y la necesidad de intervención profesional o familiar. Si bien algunas personas reconocen su problema y buscan tratamiento, otras no perciben su comportamiento como una adicción o minimizan sus efectos negativos(27). Esto plantea la cuestión de hasta qué punto es ético intervenir de manera coercitiva para proteger la salud de alguien que no solicita ayuda.

Cuando se trata de menores de edad, el dilema se torna aún más complejo. Niños y adolescentes se encuentran en una etapa crucial de desarrollo cognitivo y emocional, lo que puede dificultar su capacidad para evaluar los riesgos del comportamiento en línea. Los padres y educadores deben decidir si imponer límites estrictos, como bloquear redes sociales o videojuegos, es una medida justificada, o si, por el contrario, podría vulnerar el derecho de los menores a explorar y aprender digitalmente(32). Además, algunas investigaciones sugieren que intervenciones autoritarias pueden generar una resistencia al tratamiento y debilitar la confianza entre padres e hijos(31).

En ciertos casos, la ciberadicción está vinculada a otros trastornos, como ansiedad y depresión, lo que aumenta el riesgo de conductas suicidas(33).

Esto obliga a los profesionales a adoptar enfoques terapéuticos que respeten la autonomía del individuo, pero que también sean efectivos para prevenir daños mayores.

El monitoreo de la actividad digital es una herramienta clave para evaluar la gravedad de la ciberadicción, pero también genera dilemas sobre la privacidad y la protección de datos. Las terapias en línea y las aplicaciones de control parental pueden requerir acceso a información sensible, como el historial de navegación y las redes de contacto. Sin embargo, la supervisión excesiva puede percibirse como una invasión a la privacidad, especialmente si no existe un consentimiento informado claro que defina sus alcances y limitaciones(34).

Desde un enfoque bioético, el principio de no maleficencia debe equilibrarse con el de beneficencia. La recopilación de ciertos datos sólo debe justificarse si es estrictamente necesaria para un tratamiento efectivo, respetando los derechos de confidencialidad del paciente(32). No obstante, el manejo de estos datos por parte de terceros, como empresas tecnológicas, introduce riesgos adicionales, ya que podrían ser utilizados con fines comerciales o de vigilancia, lo que resalta la necesidad de regulaciones estrictas en protección de datos(35).

En cuanto a los menores, el control parental puede derivar en un monitoreo excesivo que afecte la confianza y el desarrollo de su autonomía digital(34). Por lo tanto, es crucial que cualquier estrategia de supervisión respete la privacidad de los menores mientras los protege de los peligros asociados con el uso excesivo de la tecnología.

Un dilema adicional es la paradoja del tratamiento digital. Muchas intervenciones contra la ciberadicción dependen de herramientas tecnológicas, como aplicaciones de autoayuda, terapia en línea e incluso programas de realidad virtual. Aunque estos recursos facilitan el acceso a la atención psicológica, también plantean la contradicción de depender de la misma tecnología que se busca regular(36).

Si bien la tele terapia permite superar barreras geográficas y brinda apoyo continuo(37), también puede reforzar el uso compulsivo de pantallas, especialmente entre los pacientes más jóvenes. Además, la proliferación de plataformas comerciales que

ofrecen tratamientos en línea sin una regulación adecuada genera preocupaciones sobre la calidad y la ética de estos servicios, ya que podrían priorizar el lucro sobre la efectividad terapéutica(30).

Etiquetar a una persona como ciberadicta conlleva implicaciones sociales y emocionales significativas. El término “adicción” tiene una connotación negativa que puede reforzar la discriminación, especialmente en un mundo donde la hiperconectividad se percibe como un rasgo de productividad y modernidad(38), lo que dificulta la distinción clara entre un uso intensivo y un uso problemático de la tecnología.

La industria tecnológica también desempeña un papel crucial en este fenómeno. Las plataformas digitales emplean estrategias de gamificación y algoritmos diseñados para maximizar el tiempo de uso, fomentando así conductas adictivas(39). Desde una perspectiva ética, es necesario debatir hasta qué punto estas empresas deberían asumir responsabilidad en la mitigación de la ciberadicción, ya sea a través de mecanismos de autorregulación o mediante regulaciones estatales más estrictas.

En definitiva, la ciberadicción puede entenderse como un problema complejo que involucra factores clínicos, tecnológicos y sociales. Para abordarlo eficazmente, es necesario encontrar un equilibrio entre la autonomía individual, la prevención del abuso digital y la intervención terapéutica. La privacidad, el derecho a la autodeterminación y la responsabilidad de las corporaciones tecnológicas son temas clave en este debate. Solo a través de un enfoque multidimensional se podrán mitigar los riesgos de la ciberadicción y promover un uso saludable de las tecnologías digitales.

Desafíos éticos en la ciberadicción

El fenómeno de la ciberadicción no solo plantea dilemas éticos, sino que también introduce desafíos que deben abordarse desde perspectivas sociales, políticas y tecnológicas, con el fin de desarrollar soluciones que respeten la autonomía individual sin desatender los riesgos asociados. Superar los dilemas previamente expuestos exige estrategias que equilibren prevención, regulación y educación digital, garantizando respuestas efectivas sin vulnerar derechos fundamentales. En este sentido, resulta

imprescindible analizar los desafíos éticos desde una perspectiva estructural que considere tanto las dinámicas de poder involucradas como los impactos sociales y normativos derivados del diseño y la gobernanza tecnológica.

Uno de los principales desafíos éticos consiste en desarrollar criterios diagnósticos consensuados que permitan diferenciar entre el uso intensivo y el uso patológico de la tecnología. La ausencia de consenso en la comunidad científica respecto de qué constituye ciberadicción genera un vacío que puede derivar en diagnósticos inconsistentes y, en consecuencia, en tratamientos inadecuados. Es necesario establecer marcos clínicos basados en evidencia empírica que permitan identificar cuándo el uso excesivo de la tecnología se convierte en una adicción y cuándo responde a factores subyacentes como ansiedad, depresión o exclusión social(27,28,30). Sin criterios claros, existe el riesgo de patologizar comportamientos que podrían formar parte de la adaptación natural a una sociedad digitalizada. Esta problemática se complejiza al observar que trastornos preexistentes, como el trastorno por déficit de atención con hiperactividad (TDAH) y la depresión, pueden aumentar la vulnerabilidad a la ciberadicción, lo que refuerza la necesidad de un diagnóstico integral(40,41).

En segundo lugar, fortalecer la educación digital como herramienta preventiva es fundamental. La ciberadicción se ve agravada por la falta de alfabetización digital crítica, lo que dificulta que las personas, especialmente los jóvenes, desarrollen hábitos de consumo tecnológico saludables. Las estrategias educativas deben ir más allá de la restricción del acceso y centrarse en capacitar a las personas para gestionar su tiempo en línea, identificar signos de dependencia y establecer límites adecuados. Esto requiere un esfuerzo coordinado entre instituciones educativas, familias y organismos gubernamentales para diseñar programas que integren el bienestar digital desde edades tempranas(42,43). La implementación de programas como ConRed ha demostrado ser efectiva en la reducción del ciberacoso y la adicción a Internet, reforzando la importancia de una educación digital estructurada desde la infancia(43).

Otro desafío relevante es la regulación de las prácticas empresariales que fomentan la adicción digital.

Muchas plataformas y aplicaciones están diseñadas para maximizar el tiempo de uso mediante algoritmos que refuerzan la interacción compulsiva. Si bien el libre mercado permite optimizar productos para captar usuarios, se requiere un marco regulatorio que garantice que estas prácticas no promuevan conductas adictivas. Esto podría implicar limitar ciertos mecanismos de gamificación y notificaciones persistentes, así como exigir transparencia en el funcionamiento de los algoritmos que configuran la experiencia digital(31,44). Estudios han evidenciado que las técnicas de persuasión utilizadas en videojuegos y redes sociales pueden activar circuitos cerebrales similares a los involucrados en adicciones químicas, lo que subraya la urgencia de regular estos mecanismos(45).

En relación con lo anterior, un desafío clave es promover la responsabilidad social corporativa en la industria tecnológica. Más allá de la regulación gubernamental, las empresas deben asumir un rol activo en la prevención de la ciberadicción. Esto implica desarrollar herramientas que ayuden a los usuarios a gestionar su tiempo en línea, fomentar pausas saludables y ofrecer información sobre el uso responsable de la tecnología. Aunque las grandes corporaciones tecnológicas tienen la capacidad de contribuir a una cultura digital más equilibrada, los esfuerzos han sido limitados(35). Algunos estudios indican que la auto exposición excesiva en redes sociales es una de las principales causas de ciberacoso y ansiedad social, lo que sugiere la necesidad de mecanismos de protección más efectivos(46,47). La ética del manejo de datos en la ciberadicción debe alinearse con principios de transparencia, consentimiento informado y respeto a la confidencialidad. En el caso de menores de edad, el control parental puede derivar en un monitoreo excesivo, generando un entorno de vigilancia que afecta la confianza y el desarrollo de la autonomía digital(34).

Otro aspecto crucial es la adaptación del tratamiento de la ciberadicción a las necesidades individuales. Muchos programas de intervención siguen modelos rígidos que no siempre consideran la diversidad de casos y contextos en los que se manifiesta la ciberadicción. Es necesario avanzar hacia enfoques personalizados que tomen en cuenta factores como edad, salud mental preexistente y entorno social. Esto implica integrar psicología,

neurociencia y educación en la formulación de estrategias terapéuticas efectivas(33,48). La literatura ha mostrado que el aislamiento social es un factor determinante en el desarrollo de conductas adictivas en adolescentes, lo que refuerza la importancia de adaptar los tratamientos a cada contexto(24).

Asimismo, un desafío de gran relevancia es el empoderamiento de familias y comunidades en la gestión del uso tecnológico. La ciberadicción no puede abordarse únicamente desde el ámbito clínico; requiere la participación “activa” de familias y comunidades en la promoción de hábitos digitales saludables. Es necesario que los padres reciban formación para establecer límites equilibrados sin recurrir a prohibiciones absolutas, y que las comunidades educativas integren el bienestar digital en sus programas de orientación. Crear espacios de conversación intergeneracionales sobre el uso de la tecnología es clave para fortalecer una cultura digital consciente y responsable(49,50).

Por último, debe considerarse el desafío de redefinir la relación entre tecnología y bienestar en un mundo crecientemente digitalizado. La tecnología puede mejorar la calidad de vida, pero su uso desmedido genera consecuencias negativas. Encontrar el equilibrio entre conectividad y salud mental es un reto que involucra a gobiernos, empresas, instituciones educativas y a la sociedad en su conjunto. Promover una visión de la tecnología que favorezca el bienestar humano sin caer en tecnofobia o restricciones innecesarias constituye uno de los mayores desafíos éticos de la era digital(38).

Así, los desafíos éticos en torno a la ciberadicción requieren respuestas integrales que trasciendan la mera identificación de dilemas y se orienten hacia soluciones viables. Desde la regulación de prácticas empresariales hasta la educación digital y la personalización de tratamientos, cada dimensión de este fenómeno exige un enfoque interdisciplinario y éticamente fundamentado. A medida que la sociedad avanza hacia una mayor digitalización, es fundamental que los esfuerzos por mitigar la ciberadicción no solo protejan a los individuos más vulnerables, sino que también promuevan una relación equilibrada y saludable con la tecnología.

Reflexiones finales

Las discusiones en torno a la ciberadicción han evidenciado la complejidad de los dilemas éticos asociados a la autonomía, la privacidad, la intervención y la responsabilidad social. No obstante, el desafío no radica únicamente en identificar estas tensiones, sino en generar mecanismos viables y respetuosos de los derechos fundamentales que permitan abordarlas de manera eficaz. La falta de consenso en la comunidad científica respecto de la delimitación conceptual de la ciberadicción subraya la necesidad de establecer criterios diagnósticos rigurosos que diferencien entre un uso intensivo y una verdadera patología(27,28). Esta dificultad en la conceptualización y el diagnóstico conlleva el riesgo de patologizar en exceso conductas tecnológicas habituales, promoviendo una visión reduccionista del fenómeno que desatiende factores sociales y culturales subyacentes(30).

Un aspecto clave para superar estos dilemas es el fortalecimiento de la educación digital y la alfabetización tecnológica como estrategias fundamentales para fomentar un uso saludable de la tecnología desde edades tempranas, mitigando riesgos sin recurrir a prohibiciones absolutas(42,43). La intervención en ciberadicción no puede limitarse a medidas restrictivas que, en ciertos casos, podrían generar efectos contraproducentes, como el aumento del estrés, la sensación de desconexión o la resistencia al tratamiento(31). En este sentido, resulta imperativo que las estrategias de prevención adopten un enfoque integral que combine educación, regulación y apoyo psicológico, con el fin de reducir el impacto de la ciberadicción en poblaciones vulnerables, especialmente niños y adolescentes(33).

A nivel estructural, uno de los principales retos radica en la regulación de la industria tecnológica y de sus prácticas de diseño digital, muchas de las cuales buscan maximizar el tiempo de uso mediante técnicas de gamificación y refuerzo intermitente, favoreciendo así la dependencia tecnológica(39). A pesar de las iniciativas orientadas a promover un uso más ético de la tecnología, la ausencia de una regulación uniforme y la resistencia de las grandes corporaciones digitales continúan dificultando avances significativos. Frente a ello, se requiere un mayor compromiso por parte de gobiernos y orga-

nismos internacionales para establecer normativas claras que limiten las prácticas de diseño adictivo y garanticen la transparencia en el manejo de datos personales(35).

En cuanto al tratamiento de la ciberadicción, el uso de herramientas digitales para la intervención, como la teleterapia y las aplicaciones de autoayuda, representa un avance significativo en la accesibilidad a los servicios de salud mental. Sin embargo, también plantea un dilema ético, al depender de la misma tecnología que se busca regular, lo que podría generar nuevas formas de dependencia o reforzar la exposición a estímulos digitales problemáticos(36). Esto exige una reflexión más profunda sobre la efectividad de estos tratamientos y la necesidad de combinarlos con intervenciones presenciales que permitan evaluaciones más personalizadas y un acompañamiento terapéutico adecuado(51).

Finalmente, la ciberadicción no solo constituye un desafío clínico y tecnológico, sino también un fenómeno social que incide en la construcción de identidad, el bienestar emocional y la calidad de las relaciones interpersonales. En este sentido, su abordaje requiere un enfoque interdisciplinario que integre a familias, comunidades educativas, profesionales de la salud y actores del sector tecnológico.

La transformación digital ha redefinido las formas de comunicación y entretenimiento, generando nuevas vulnerabilidades que demandan respuestas dinámicas y adaptativas. Superar los desafíos éticos asociados a la ciberadicción implica no solo implementar regulaciones y tratamientos efectivos, sino también sostener una reflexión continua sobre el papel que la tecnología debe desempeñar en la vida humana. La meta no es eliminar su uso, sino asegurar que se convierta en una herramienta que potencie el desarrollo personal y social sin generar nuevas formas de dependencia y exclusión(47).

En conclusión, la ciberadicción emerge como un fenómeno inseparable de la era digital, cuyo abordaje exige un replanteamiento constante de las estrategias de prevención y regulación. A través de un enfoque basado en la ética, la educación y la corresponsabilidad de todos los actores implicados, es posible mitigar sus riesgos y garantizar que la tecnología se utilice para promover el bienestar humano y no como una fuente de vulnerabilidad.

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ARTIFICIAL INTELLIGENCE IN DEFENSE: A BIOETHICAL EXAMINATION OF SOCIETAL RISKS AND GOVERNANCE

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Abstract: This paper explores the societal risks that may arise from the integration of artificial intelligence (AI) into defense innovations and examines how the principle of responsibility can be achieved in this context. Using a qualitative descriptive-analytical approach grounded in international reports and prior studies, the paper identifies four critical domains of societal risk: threats to human life, terrorist misuse, cyber and electronic warfare, and the lack of accountability for actions committed by autonomous or semi-autonomous systems. To address these challenges, a tri-level framework of responsibility is proposed —international, institutional, and socio-cultural— linking global ethical norms with local governance practices and moral values. The study argues that responsible innovation in AI-driven defense technologies requires ethical governance that ensures accountability, human oversight, and societal legitimacy, thereby balancing security imperatives with public trust.

Keywords: Artificial Intelligence, defense, societal risks, governance

Inteligencia Artificial en defensa: un examen bioético de los riesgos sociales y la gobernanza

Resumen: Este artículo explora los riesgos sociales que pueden surgir de la integración de la inteligencia artificial (IA) en innovaciones en defensa y examina cómo se puede lograr el principio de responsabilidad en este contexto. Utilizando un enfoque descriptivo-analítico cualitativo, basado en informes internacionales y estudios previos, el artículo identifica cuatro dominios críticos de riesgo social: amenazas a la vida humana, uso indebido de terroristas, guerra cibernética y electrónica, y la falta de rendición de cuentas por acciones cometidas por sistemas autónomos o semiautónomos. Para abordar estos desafíos, se propone un marco de responsabilidad a tres niveles —internacional, institucional y sociocultural— que vincule las normas éticas globales con las prácticas de gobernanza local y los valores morales. El estudio sostiene que la innovación responsable en tecnologías de defensa impulsadas por IA requiere una gobernanza ética que garantice rendición de cuentas, supervisión humana y legitimidad social, equilibrando así los imperativos de seguridad con la confianza pública.

Palabras clave: Inteligencia Artificial, defensa, riesgos sociales, gobernanza

Inteligência Artificial na defesa: um exame bioético dos riscos sociais e da governança

Resumo: Este artigo explora os riscos sociais que podem surgir da integração de inteligência artificial (IA) em inovações de defesa e examina como o princípio da responsabilização pode ser alcançado nesse contexto. Utilizando uma abordagem descritiva-analítica qualitativa, baseada em relatórios internacionais e estudos anteriores, o artigo identifica quatro domínios críticos de risco social: ameaças à vida humana, uso indevido de terroristas, guerra cibernética e eletrônica, e falta de responsabilização por ações cometidas por sistemas autônomos ou semi-autônomos. Para enfrentar esses desafios, é proposto um quadro de responsabilidade em três níveis —internacional, institucional e sociocultural— que conecta padrões éticos globais com práticas de governança local e valores morais. O estudo argumenta que inovação responsável em tecnologias de defesa alimentadas por IA requer governança ética que garanta responsabilidade, supervisão humana e legitimidade social, equilibrando assim imperativos de segurança com confiança pública.

Palavras-chave: Inteligência Artificial, defesa, riscos sociais, governança

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Introduction

The world is experiencing an unprecedented acceleration in the development of artificial intelligence (AI) technologies, which have become a defining feature of the contemporary era and an integral component of economic, social, security, and defense domains. However, this rapid advancement is accompanied by serious risks. Omohundro(1) warns that intelligent systems—even those designed with relatively simple objectives—may engage in harmful behaviors if not adequately constrained. These risks are further intensified within the defense sector, where Bostrom(2) and Altmann and Sauer(3) caution that AI may be employed in the development of autonomous weapons or in the conduct of military operations that bypass international norms, thereby threatening both national and global security. In this context, Thurnher(4) argues that the deployment of such systems in armed conflicts raises profound legal and ethical dilemmas that undermine their legitimacy.

Beyond these concerns lies a more complex challenge known as **responsibility gaps**. Intelligent systems may generate outcomes that are difficult to predict, control, or fully comprehend, raising fundamental questions regarding accountability. Several scholars describe this phenomenon as an ethical and legal vacuum that threatens core principles of justice and responsibility(5-8). Consequently, the risks posed by AI extend beyond immediate security threats to challenge the moral foundations of social and political systems.

In response to these challenges, international institutions have begun to develop global regulatory frameworks. Most notably, UNESCO adopted the *Recommendation on the Ethics of Artificial Intelligence* in 2021(9), the first international instrument aimed at guiding AI development in accordance with human rights, justice, transparency, and human oversight. Similarly, several scholars emphasize the need to reconcile technological progress with the ethical foundations of society(10,11). These initiatives align with the warnings of physicist Stephen Hawking, who cautioned that the development of advanced AI without ethical, legal, and human safeguards could pose an existential threat to humanity(12,13).

This study does not focus on a specific military AI technology; rather, it addresses risks wherever they arise across diverse AI-enabled defense applications, given their shared ethical and security challenges. It seeks to fill a significant gap in the literature by offering a comprehensive critical analysis of the risks associated with AI-driven defense innovations, particularly in light of intensifying strategic competition among states and growing concerns over the lack of accountability and governance resulting from increased system autonomy(14,15).

The study is grounded in a theoretical framework that links the risks of AI-based defense innovations to the principle of **responsibility**, understood through ethical values as the primary reference for regulation. Existing literature indicates that defense-related AI systems may threaten human life, facilitate terrorism, expand cyber warfare, and generate profound responsibility gaps that complicate the attribution of blame and accountability(2-6). Such risks cannot be adequately addressed through technical or legal measures alone; rather, they require a moral and ethical framework grounded in values such as human dignity, justice, transparency, and fairness. These values may be operationalized at multiple levels: the international level through treaties and ethical frameworks(9), the institutional and regulatory level through oversight and legislation(16), and the socio-cultural level through community engagement in shaping the values governing defense applications(17,18).

Accordingly, this study proceeds from the assumption that **ethical responsibility** constitutes the unifying thread between AI-related risks and defense innovations, and that effective regulation of such innovations can only be achieved by aligning technological advancement with shared human values. In light of this premise, the paper seeks to address the following research questions:

What societal risks arise from AI-driven defense innovations? How can the principle of responsibility be achieved in AI-driven defense innovations?

Responsibility Gaps in AI Systems

In this study, responsibility is defined as the relationship between an agent, their actions, and the

resulting consequences(19,20). A growing body of literature has examined responsibility gaps in both military and non-military AI systems. Hellström(21) argues that automation weakens direct human accountability, creating a legal and ethical void, while Noorman and Johnson(22) maintain that the overlapping roles of humans and machines complicate the attribution of individual or collective responsibility. Purves, Jenkins, and Strawser(23) warn that delegating combat decisions to autonomous systems threatens long-standing principles of justice in warfare. Leveringhaus(24) further emphasizes the responsibility of political and military leadership to establish strict safeguards prior to the deployment of such systems.

Himmelreich(25) extends this debate by asserting that responsibility gaps are not merely legal but also ethical, as the inability to identify a clearly accountable agent undermines the legitimacy of future warfare. In a similar vein, Danaher(19) introduces the concept of the **Retribution Gap**, which arises when no moral or legal offender can be clearly identified following harm caused by intelligent systems, thereby eroding trust in justice. Königs(14) adds that the multiplicity of actors involved in AI systems—such as developers, manufacturers, vendors, and users—further complicates the accurate distribution of responsibility. Sparrow(26) observes that ethical controversy surrounding Autonomous Weapon Systems (AWS) has intensified since the 2012 *Human Rights Watch* report and the subsequent international campaign to ban such systems, while noting that limited moral permissibility may exist in highly constrained contexts.

By contrast, Königs(14) adopts a more skeptical stance toward the responsibility gap thesis, arguing that such gaps may be inevitable in theory but insufficiently defined in practice. He contends that concerns about responsibility gaps are often overstated, as there are contexts in which they are unlikely to arise. This position aligns with several studies that question either the inevitability or the significance of responsibility gaps(27-32). These scholars argue that responsibility gaps emerge only in cases where harm cannot be attributed to negligence, malice, or wrongful intent, and that negligent use of autonomous systems remains morally blameworthy.

This debate reveals a fundamental dilemma in defending the concept of responsibility gaps: either one must assume that system autonomy exempts humans from responsibility even in cases of negligence—which is implausible—or accept that responsibility generally remains attributable to human agents, rendering responsibility gaps rare and difficult to identify. It is also notable that much of the literature has focused primarily on the negative dimension of responsibility(33,34). More recent work, however, has expanded the discussion to include the positive dimension of responsibility, such as attributing credit for beneficial AI outcomes(35-38). Nevertheless, the present study limits its scope to negative responsibility due to its direct relevance to the risks under consideration.

Literature Review

The deep integration of AI into various aspects of human life has generated significant academic interest, particularly with regard to its implications for security and societal stability. While a substantial portion of the literature addresses AI-related risks to ethical and religious values in broad terms, comparatively fewer studies focus specifically on security, defense, and warfare-related risks, especially those emerging alongside rapid advances in autonomous and electronic capabilities.

From a defense perspective, Sparrow(6) and Thurnher(4) argue that autonomous weapons pose a direct threat to human life by undermining the moral and legal foundations of warfare. Bostrom(2) and Altmann and Sauer(3) warn that AI may be exploited to facilitate terrorism and illicit activities, thereby amplifying threats to global security. Johnson(39) and Santoni de Sio and Mecacci(40) highlight the expansion of cyber and electronic warfare, emphasizing that unclear accountability increases the likelihood of irresponsible use. Danaher(19), Himmelreich(25), and Nyholm(7) further stress the complexity of legal and moral responsibility in AI-enabled defense contexts, while Buhmann and Fieseler(41) propose frameworks for responsible AI innovation.

Beyond defense, scholars note that accelerated digitalization places increasing pressure on public values, underscoring the need for proactive governance mechanisms(15,42-44). Religious and ethi-

cal studies suggest that AI may reshape spiritual practices and cultural authority, potentially weakening traditional religious structures while also enabling new forms of dialogue(45-49). Moreover, societal trust in AI systems is closely tied to transparency, human oversight, and adherence to ethical values(47,9).

Overall, the literature indicates that most studies have addressed AI either from technical perspectives or from ethical and social viewpoints disconnected from defense applications. Although defense-related risks have been acknowledged, the relationship between such risks and ethical values as a foundation for responsibility-building remains insufficiently articulated. Accordingly, this study seeks to address this gap by examining four key defense-related risks—threats to human life, terrorism, cyber warfare, and responsibility gaps—and by proposing practical levels for operationalizing responsibility within an integrated ethical and defense-oriented framework.

Methodology

This paper adopts a qualitative descriptive-analytical approach through a systematic examination of relevant literature, previous studies, and international reports on artificial intelligence and its associated risks—particularly in the domains of defense and security innovations. The literature was selected based on specific criteria, including recency of publication (with emphasis on works published after 2010), direct relevance to defense-related AI or ethical and legal responsibility dimensions, and citation frequency, in addition to sources issued by authoritative international institutions such as the European Union, UNESCO, and the International Committee of the Red Cross.

The search process was conducted across major academic databases such as *Scopus*, *Web of Science*, *Springer*, and *IEEE Xplore*, in addition to reports issued by specialized research centers. The paper identifies and synthesizes the most prominent risks extracted from this analysis, with particular focus on the dangers associated with AI-driven defense innovation. Beyond merely identifying risks, the study advances toward proposing mechanisms for operationalizing responsibility in

such innovations across three integrated levels: the international level, the institutional—regulatory level, and the socio-cultural level.

Study Limitations

This paper is limited to addressing *negative responsibility* associated with the defensive risks of artificial intelligence and does not examine *positive responsibility* or cases in which intelligent technologies are credited with success. The analysis is confined to available literature without incorporating field-based or technical experimental research, which aligns with the theoretical nature of this study that aims to construct an initial analytical framework—one that may serve as a foundation for future research with deeper empirical or technical engagement. Additionally, the paper does not delve into the algorithmic or engineering intricacies of AI systems; rather, its scope is restricted to identifying defense-related risks and outlining mechanisms for enforcing responsibility within this domain.

Results and Discussion

The Societal Risks of AI-Driven Defense Innovation

Sparrow(26) argues that the development of autonomous weapons systems is nearly inevitable, driven by a combination of military and political incentives that encourage the adoption of technologies capable of independently performing combat operations—including the use of lethal force without direct human intervention. Project Maven in the United States is considered one of the most prominent initiatives aimed at accelerating the integration of artificial intelligence and machine learning into U.S. military operations (50). Scharre (51) employs the term *race to the bottom* to describe the intense competition among states that may lead them to lower safety standards or disregard ethical and regulatory frameworks in pursuit of rapid armament and strategic advantage. Based on the qualitative analytical approach adopted in this study, the most salient risks associated with AI-based defense innovation can be identified as follows:

Threats to Human Life

Sacred traditions have long affirmed the inviolability of human life, considering any violation thereof an act of moral and social corruption. Respect for human life is foundational to social security and psychological stability and is recognized as the most fundamental of human rights. All modern states and international bodies uphold this principle without discrimination on the basis of religion, race, or language. Article 3 of the Universal Declaration of Human Rights explicitly states that “*Everyone has the right to life, liberty and security of person*”(52).

Despite the developmental opportunities offered by artificial intelligence, it has increasingly become a source of existential concern among experts, who warn that it may evolve into a direct threat to humanity. Several prominent technology leaders have voiced such fears. Elon Musk, for instance, cautioned that AI could potentially ignite a future world war(53), while Stephen Hawking warned that developing full artificial intelligence without adequate ethical and legal safeguards could lead to human extinction(54).

Strategic actions taken by global powers lend further credibility to these warnings. China, for example, has announced its intention to become the world leader in AI by 2030, capturing nearly 60% of global investments between 2013 and 2018(55). Russia aims to convert 30% of its military equipment into robotic systems by 2025(56), while the United States adopted a comprehensive strategy in 2018 to accelerate AI integration across all branches of its armed forces(57).

Al Dehshan(58) notes that such rapid military adoption of autonomous systems—such as robots and unmanned aerial vehicles—increases the likelihood of catastrophic errors beyond human control. Similarly, Sparrow (6) contends that delegating combat decisions to machines raises profound ethical and legal dilemmas, particularly regarding accountability for war crimes, thereby undermining legal deterrence and fundamentally transforming the nature and conduct of warfare.

Expert estimates further suggest that even a small probability of achieving human-level artificial gen-

eral intelligence—estimated at only 3%—is sufficient to classify its risks as existentially significant. Some forecasts indicate that this probability may exceed 50% by 2050(47). Moreover, several legal studies argue that autonomous weapons lack the full capacity to distinguish between civilians and combatants, or between healthy and wounded soldiers, rendering their deployment—especially in urban settings—highly controversial under international humanitarian law(4).

Terrorist Exploitation

This paper contributes to expanding the discussion surrounding the growing potential for artificial intelligence (AI) to be exploited in terrorist operations by linking this dimension to the risks of defense innovation—an analytical perspective that adds depth to existing literature addressing this issue (2,61). As extremist groups increasingly adopt modern technologies for propaganda, recruitment, and operational execution, it is no longer plausible to dismiss the possibility that AI may eventually be weaponized to facilitate more precise and destructive forms of terrorism. This likelihood becomes even more realistic amid escalating geopolitical tensions and the emergence of new conflict zones, which often provide fertile ground for radical ideologies and the formation of extremist cells.

Recent literature highlights that AI’s exceptional capabilities in simulation, strategic planning, cyber intrusion, and deepfake manipulation make its weaponization by terrorist groups an imminent threat worthy of serious attention. Extremist actors have already begun experimenting with such tools for propaganda and operational planning. Ahmed (59) confirms that contemporary extremism has increasingly benefitted from the digital environment to amplify its activities. Abdel Wahab et al.(60) document how ISIS utilized explosive-laden drones to carry out attacks and targeted assassinations, including the attempted strike on Venezuelan President Nicolás Maduro during a military parade in 2018. Bullen(61) further warns of the dangers posed by drone systems enhanced with facial recognition technologies for conducting precision assassinations. In a more recent incident, former soldier Matthew Levinson was convicted of using AI technologies—including

ing ChatGPT—to plan the detonation of a Tesla truck outside the Trump Hotel in Las Vegas(62).

Thus, AI-enabled terrorism is no longer a hypothetical concern but an escalating threat advancing in parallel with the rapid evolution of defense innovations. This underscores the importance of the present paper in drawing attention to a highly sensitive security dimension—one that demands urgent legislative, ethical, and security interventions to prevent the diversion of AI technologies toward terrorist exploitation, especially amid intensifying strategic competition among global powers and increasing fragility in international security.

Cyber and electronic warfare

The literature warns that responsibility gaps in autonomous systems extend beyond conventional military domains into the realm of cyber and electronic warfare. Sparrow (6) cautions that delegating decisions to autonomous systems may lead to consequences that fall outside the scope of traditional war crimes. Johnson(39) argues that assigning responsibility to individuals helps maintain pressure on developers to ensure system safety and reliability—highlighting a serious risk whereby detachment from responsibility may incentivize developers toward profit-driven neglect. Santoni de Sio and Mecacci(40) similarly warn that the ease with which designers and operators can evade blame reduces incentives to prevent harmful outcomes, posing a particularly acute risk in cyberattacks where intelligent systems are capable of obfuscation and large-scale damage without a clearly identifiable perpetrator.

The threat of AI-driven cyber warfare has expanded far beyond the conventional use of autonomous systems. Research now points to the development of *automated hacking systems* capable of independently discovering vulnerabilities, generating malware, and executing integrated attacks without human intervention—complicating legal and ethical accountability and rendering damage more opaque and difficult to trace(63). This risk is further exacerbated by the rise of *adversarial attacks* and *model poisoning*, where attackers manipulate data or train systems toward erroneous behavior that leads to catastrophic decisions. Recent

reports indicate that such attacks may be used to disable sensitive defense or surveillance infrastructure, including energy, water, and transportation networks—potentially resulting in severe human and material losses(64).

Moreover, the informational dimension represents one of the most dangerous outputs of AI in cyber warfare. Deepfake technologies can now be deployed to launch large-scale disinformation campaigns, incite extremist rhetoric, and disrupt political and social processes. What makes this phenomenon particularly dangerous is its ability to undermine trust in institutions and inflame internal divisions—without the need for any direct military confrontation(65). Compounding the issue is the *black box problem* inherent in AI systems: many models operate as opaque structures whose decision-making processes are difficult to interpret even by their creators. This opacity complicates the attribution of fault or responsibility when AI systems are weaponized in cyber warfare—especially when the resulting harm is non-physical, such as media manipulation or societal mistrust(66).

Additionally, commercial incentives and the competitive race among global powers to develop AI-enhanced cyber capabilities further amplify the risks. Under mounting economic and political pressure, safety standards and ethical controls may be relaxed—leading to the production of advanced offensive systems without adequate oversight or transparency. This scenario foreshadows an unprecedented cyber arms race that could drastically increase the likelihood of large-scale disasters that are difficult to contain(67).

Absence of Responsibility for Committing Crimes

Earlier sections discussed responsibility gaps in artificial intelligence as a concept that has sparked significant philosophical and legal debate. However, this issue is no longer merely theoretical—it has become a tangible threat imposed by the rapid acceleration of AI technologies. As intelligent systems grow more complex and their outputs become increasingly unpredictable or difficult to control, the fear of *absent accountability* emerges as one of the most pressing challenges to both hu-

manity and society.

Legal systems across human civilizations rest on the foundational principle that an agent must be held accountable for their actions—whether civilly through compensation or criminally through punishment. Yet, the introduction of intelligent machines into this equation has fundamentally disrupted this paradigm. In autonomous vehicle incidents such as the well-known Elaine Herzberg case(68), a pressing question arises: *Who is responsible for the error?* The absent human driver? The programmer? The manufacturing company? Or the AI system itself, which cannot be punished or prosecuted?(69).

This dilemma becomes even more severe when transferred from civilian settings to the defense domain, where mistakes or crimes may have catastrophic consequences. If an autonomous combat system were to carry out an indiscriminate attack on civilians, or make a lethal decision beyond human instruction, *who could be held accountable?* A robot cannot be subjected to criminal sanctions, and assigning full responsibility to developers or military authorities may not always be justifiable—particularly given the complexity of production and operational networks and the multiplicity of actors involved. Here, the contours of what is termed the *responsibility gap* become evident: the absence of a clearly attributable agent capable of bearing moral or legal blame, resulting in an unprecedented ethical and judicial vacuum.

This issue transcends legal debate to constitute an existential threat to human security. As reliance on AI in defense contexts increases, individual mistakes may escalate into collective disasters—endangering lives, destabilizing global peace, and undermining fundamental principles of justice and humanity. With the continued advancement of these technologies, the danger posed by crimes committed under conditions of absent accountability will only expand across political, military, economic, and social domains.

Accordingly, there is an urgent need to develop new ethical and legislative frameworks that ensure fair attribution of responsibility—whether through holding political and military leaders accountable, establishing legal mechanisms that

assign partial liability to corporations and developers, or adopting international standards that re-anchor defense innovations within the bounds of international humanitarian law. Failure to establish such frameworks would render the responsibility gap a *ticking time bomb*, exposing humanity to unprecedented risks in its history.

Achieving the Principle of Responsibility in AI-Driven Defense Innovation

While some voices emphasize the potential of artificial intelligence—particularly in Autonomous Weapon Systems (AWS)—to eventually exhibit greater adherence to ethical norms in warfare than humans themselves, as suggested by Arkin(70), other scholars express profound concerns regarding such capabilities. Peters(71) argues that the internal factors guiding these systems' decision-making processes remain largely opaque to humans due to their computational complexity, creating uncertainty around their actions. Nevertheless, there appears to be broad consensus on the urgent need for practical and regulatory measures to confront—or at least mitigate—the serious consequences of unsafe AI deployment in defense and security domains. Although completely eliminating these risks may be impossible, continued efforts remain a moral and social obligation shared across all societal institutions, governments, and relevant stakeholders. Each actor bears a role in anticipating risks, proposing adequate safeguards, and developing effective responses should such threats materialize.

Determining who should be responsible for ensuring that AI systems align with human values and objectives—and for safeguarding the principle of responsibility—remains an ongoing debate. Nyholm(72) notes that it is not yet clear *who* should be tasked with designing and implementing the necessary frameworks and legislation to guarantee such alignment, reflecting an institutional and ethical gap that has received insufficient attention in current value alignment discourse(73,74). Accordingly, the ambiguity surrounding the actors responsible for establishing such frameworks directly raises the second question of this study: *How can the principle of responsibility be operationalized in AI-driven defense innovations?* To address this, it becomes necessary to analyze the different levels at

which responsibility may be enacted as an entry point for addressing this gap.

The concept of responsibility clearly reflects the reciprocal dynamics among the three core dimensions identified in this study: society, ethics, and AI-based defense innovation. The findings reveal that responsibility serves as the unifying thread connecting these dimensions across multiple levels—namely: the *international level*, which bears responsibility for ensuring that defense innovation adheres to universal standards; the *societal level*, which assumes responsibility for regulating usage and shaping public expectations; and the *institutional-regulatory level*, which is tasked with establishing ethical frameworks, rules, and criteria governing AI deployment. These levels will be discussed as follows:

The international level

The year 2021 witnessed increasing calls from major global powers—including the United States, China, and European Union member states—to establish an international charter defining the ethical principles governing the use of artificial intelligence (AI), grounded in values such as justice, transparency, and respect for human rights (75). Parallel to these efforts, significant regional initiatives emerged—most notably the European experience, which established strict legal standards for data protection and privacy, rooted in Western legal traditions that seek to contain technological risks through binding frameworks.

Several countries have since launched national strategies inspired by these principles and adapted to local priorities. A prominent example is the Kingdom of Saudi Arabia's *National Strategy for Data and Artificial Intelligence* (SDAIA, 2023) (76), which emphasizes justice, privacy, transparency, and accountability as foundational pillars for responsible AI deployment. In this context, the Political Declaration on Responsible Military Use of Artificial Intelligence, launched by the United States in 2023 with the participation of more than fifty countries, represented an important step toward building international consensus. The declaration focused on establishing guiding principles for the use of autonomous systems and artificial intelligence in defense, most notably: strengthen-

ing human oversight, ensuring compliance with international humanitarian law, and avoiding applications that undermine human dignity or increase the risk of uncontrolled military escalation. Although it is not legally binding, the declaration reflects a growing trend toward establishing shared ethical standards that may pave the way for broader international cooperation and, eventually, more binding agreements(77).

However, despite the global dominance of such international and Western frameworks, their implementation remains subject to the cultural and religious specificities of each nation. This underscores the need to acknowledge the influence of these contextual factors in shaping ethical standards. Accordingly, distinctive local models have emerged—such as the Islamic perspective—which offers a unique ethical framework for AI that may enrich the global conversation by broadening it to include diverse moral paradigms.

Although international efforts have made significant progress in formulating general ethical guidelines for AI use in civilian and societal domains, the challenge becomes more pronounced when transitioning to the defense sector. AI-driven military innovations raise more urgent questions regarding control and governance due to their direct implications for national security and global peace. This defensive dimension has become a growing concern for many states, particularly in the absence of clear legislation defining the boundaries of responsibility and accountability, highlighting the urgent need for specialized regulatory frameworks.

The European Union's *AI Act* provides an illustrative example of how establishing stringent legal standards—based on risk classification—can help reduce ethical and security threats (78). A comparison between key global initiatives reveals notable differences in foundational philosophy: the former adopts a legal-technical Western model prioritizing risk categorization, while the latter seeks value alignment rooted in cultural and religious identity. This divergence indicates that international frameworks, despite their ambition, may fail to fully account for moral plurality—making the inclusion of local contexts essential for ensuring responsibility in defense innovation.

Table 1. Comparative Overview of Prominent International and National AI Governance Initiatives

Initiative	Authority / Year	Primary Focus Area	Strengths	Limitations / Challenges
UNESCO Recommendation on the Ethics of Artificial Intelligence	UNESCO – 2021	Global framework based on justice, transparency, and human rights	First comprehensive international document on ethical dimensions, widely endorsed	Non-binding general principles; limited enforceability, particularly in defense contexts
EU Artificial Intelligence Act (EU AI Act)	European Union – 2024	Classification of AI systems based on risk levels	Legally binding, strict standards, strong focus on technical governance	Primarily centered on European context; insufficient consideration of cultural and religious diversity
National Strategy for Data and Artificial Intelligence (SDAIA)	Saudi Arabia – 2023	Responsible AI for development and security	Incorporates principles of justice, privacy, transparency, and accountability with reference to Islamic values	Limited to domestic scope; requires clearer linkage with international defense governance frameworks
Political Declaration on Responsible Military Use of Artificial Intelligence	United States and Partners – 2023	Regulating military AI and autonomous systems	Introduces political constraints on military AI use; promotes international cooperation	Non-binding; lacks clear enforcement and monitoring mechanisms

To illustrate the strengths and limitations of such initiatives, Table 1 presents a brief comparative overview, highlighting their diversity and the difficulty of formulating a unified global framework to govern military AI applications.

The comparative analysis above illustrates the complexity of achieving responsibility in military AI governance and underscores the need for more comprehensive frameworks that transcend legal and cultural divergences. In response, this paper proposes a set of models that may serve as a robust foundation for guiding international efforts toward more holistic responsibility mechanisms in the defense sector:

Ethical Review and Shared Responsibility Framework for Pre-Deployment Assessment of Defense AI Projects

Implementation Mechanism: Governments should be mandated to establish national regulations requiring all AI-based defense projects to undergo formal ethical review before approval. Moreover, the principle of Shared Responsibility should be enforced between civilian developers of AI systems and the military institutions that deploy them, ensuring that no party is able to evade legal or moral accountability in the event of violations. A practi-

cal example of such implementation can be found in the United Kingdom's adoption of *ethical assessments* within its Ministry of Defence governance framework, which evaluates reliability, transparency, justice, and human rights considerations throughout the system's lifecycle(79).

Federal/National Accountability and Oversight Framework with Independent Auditing Mechanisms

Implementation Mechanism: National legislation should require defense institutions and AI system developers to establish independent auditing units or oversight offices responsible for evaluating ethical and legal compliance both before and after system deployment. A practical precedent for this approach is reflected in the *GAO Accountability Framework for Artificial Intelligence*(80), in which the United States outlined four core pillars of AI accountability concerning governance, data, performance, and monitoring, accompanied by concrete recommendations for impact evaluation and implementation(80).

Legally-Binding International Political Declaration on Responsible Military Use of AI

Implementation Mechanism: Existing political declarations should be elevated into binding in-

ternational treaties, rather than remaining voluntary statements, in order to secure both political and legal commitment. International cooperation must be strengthened through cross-border agreements regulating AI use in military operations and curbing arms race dynamics in this domain(3). A practical example is the *Political Declaration on Responsible Military Use of Artificial Intelligence and Autonomy*, signed by the United States and several other nations, which seeks to establish an international consensus on responsible deployment and constraints on autonomous weapons systems(77).

Legal Framework Reinforcing the Link Between International Humanitarian Law (IHL) and Military AI Governance

Implementation Mechanism: Standard-setting procedures should stipulate that any deployment of autonomous systems must comply with International Humanitarian Law, supported by auditing mechanisms to verify such compliance. A relevant model has been proposed by Alexander(81), who advocates for a governance framework balancing AI alignment with international human rights law and algorithmic accountability principles.

Governmental and Societal Training and Awareness Initiatives to Foster a Shared Understanding of Responsibility

Implementation Mechanism: Mandatory training programs should be introduced for defense personnel, legislative bodies, and innovation teams to enhance ethical awareness and deepen understanding of technical risks. The *Geneva Academy Report on Artificial Intelligence and Related Technologies in Military Decision-Making* highlights the importance of empowering defense decision-makers to understand the capabilities and limitations of AI Decision Support Systems, while educating military users on ethical issues concerning bias, prediction, and explainability(82).

The socio-cultural level

The socio-cultural dimension demonstrates that achieving responsibility in AI-driven defense innovations is not limited to regulating laws and policies alone; rather, it depends on the extent to which societies are able to actively participate in

shaping the values that guide such technologies. Cath(17) and Coeckelbergh(18) affirm that integrating cultural and religious dimensions into AI development enhances justice and prevents marginalization, while Müller and Bostrom(47) argue that societal trust is fundamentally linked to clear human oversight and adherence to ethical values. In this regard, Al Dehshan(58) stresses that one of the European Union's foremost requirements is the establishment of monitoring and supervisory mechanisms that ensure intelligent systems never exceed the bounds of human control—an essential foundation for building public trust in such technologies. Stahl et al.(42) likewise caution that the accelerating wave of digitalization is placing increasing pressure on public values, necessitating a proactive approach grounded in dialogue and informed policymaking.

At the global level, the Asilomar AI Conference (Future of Life Institute, 2017) produced 23 guiding ethical principles, most notably the preservation of human control, ensuring transparency, upholding accountability, and preventing an arms race in autonomous weapons. These principles are intended primarily to reassure societies that technology exists in their service—not at their expense(83). In the same vein, Sparrow(26) warns that militarized competition may hasten the development of Autonomous Weapon Systems (AWS), in direct conflict with the ethical understanding of human dignity. Public opinion surveys further reinforce this stance, revealing widespread societal rejection of granting robots the authority to kill(84). UNESCO(9) similarly emphasizes that involving communities in AI-related deliberations enhances policy acceptance and reduces cultural misinterpretation.

However, Gabriel(73) and Nyholm(72) raise an important concern: value alignment is neither straightforward nor easily achieved. Determining *which* values, goals, or interests AI systems should embody—and *whose* values should prevail in the face of disagreement—introduces the risk of power struggles in which certain groups impose their values at the expense of others. This presents profound socio-cultural risks that demand more inclusive approaches to ensure responsible use. To contextualize these perspectives comparatively, Table 2 below presents key initiatives and stud-

ies addressing the socio-cultural dimension of AI in defense, outlining their focus areas, strengths, limitations, and implications for responsibility.

The comparison in Table 2 indicates that achieving responsibility in the socio-cultural dimension requires more than regulatory frameworks; it depends on enabling societies to take part in shaping values and standards, ensuring effective human oversight, and respecting cultural and religious diversity. However, the primary challenge lies in translating these principles from social acceptance into institutional and legislative commitments capable of governing defense innovations in practice. Accordingly, this paper proposes the following guiding principles to support the operationalization of responsibility at the socio-cultural level:

Structured Community Participation: Involving experts, religious leaders, and civil society organizations in policymaking and in reviewing AI defense applications to assess their impact on shared ethical and religious values.

Value and Cultural Diversity in Design: Adopting design methodologies that account for religious and cultural plurality from the early stages of sys-

tem development to reduce bias and ensure fairness.

Effective Human Oversight: Reinforcing the human role as supervisor and decision-maker across all stages of the AI system lifecycle to strengthen trust and transparency.

Public Ethical Audits: Conducting regular assessments of AI systems' societal and moral impact and publishing results to ensure accountability.

Ethical and Cultural Education: Integrating religious and moral dimensions into educational and training programs to foster societal understanding of emerging technologies and prevent cultural misinterpretation.

The Institutional and Regulatory Level

The institutional and regulatory dimension represents one of the most critical levels in addressing the risks of AI-driven defense innovations. Ethical principles and general declarations are insufficient unless translated into concrete structures and actionable mechanisms capable of mitigating real-world harms. In this context, Project Maven illustrates the ethical and institutional challenges

Table 2. Comparative Overview of Key Approaches in the Socio-Cultural Dimension of AI in Defense

Initiative / Study	Primary Focus	Strengths	Limitations	Implication for Responsibility
Cath (2018)	Linking AI development to social, cultural, and religious norms	Enhances justice and prevents marginalization	Lacks practical implementation mechanisms	Affirms that respecting social norms is essential for societal responsibility
Coeckelbergh (2020)	Emphasizing cultural and religious diversity	Reduces conflict and misunderstanding	Remains largely theoretical	Highlights value pluralism as part of societal responsibility
Müller & Bostrom (2016)	Building public trust through human oversight	Links responsibility to transparency and human control	Does not address direct military challenges	Human oversight as a core pillar of responsible governance
UNESCO (2021)	Community participation in policymaking	Strengthens social legitimacy and acceptance	Cultural variation complicates application	Public participation reinforces ethical accountability
Sparrow (2016) & Charli (2013)	Ethical objection to autonomous killing and public rejection of robot use of lethal force	Reveals global societal stance against human dignity violations	Difficulty translating moral stances into legal obligations	Societal responsibility manifests in rejecting violations of human dignity

of adopting AI in defense. It faced internal resistance from Google employees who rejected the use of the company's technologies for military purposes, ultimately leading to the annulment of the contract. This example highlights the complexity of the relationship between civilian and military actors and the necessity of establishing clear institutional frameworks that align defense innovations with societal and ethical values(50). Similarly, analyses of national AI policies reveal that most countries focus on education, technology, and government investment, while ethical and regulatory dimensions—particularly the design of responsible algorithms and institutional accountability mechanisms—remain marginalized and underdeveloped, underscoring the need for more comprehensive and inclusive governance approaches (85). Abdelrazek(13) argues that the existence of unified technical and ethical standards among manufacturers, owners, and end-

users contributes to ensuring safety, justice, and transparency. However, the current reality reveals serious shortcomings. Calo et al.(16) emphasize that the existing legal and regulatory infrastructure remains inadequate to keep pace with the rapid evolution of AI and the rise of autonomous defense systems.

Although the European experience in data protection—most notably through the General Data Protection Regulation (GDPR)—marked significant progress in addressing risks related to profiling, it remains insufficient in the defense context, as it does not adequately cover fundamental issues such as discrimination, human dignity, and loss of human control. Similarly, the efforts of the European Data Protection Supervisor (EDPS, 2015, 2016; EU, 2016)(86-88) have largely remained within the realm of ethical initiatives without evolving into binding institutional policies, while

Table 3. Comparative Overview of Key Institutional–Regulatory Approaches to AI in Defense

Initiative / Study	Primary Focus	Strengths	Limitations	Implication for Responsibility
Abdelrazek (2024)	Need for technical and ethical standards across manufacturers, owners, and users	Highlights shared responsibility among all actors	Lacks binding enforcement mechanisms	Institutional responsibility must be distributed rather than centralized
Calo et al. (2016)	Identifying gaps in existing legal and regulatory infrastructure	Clearly exposes deficiencies in current laws	Does not offer concrete solutions	Emphasizes need to modernize regulatory structures
GDPR (EU, 2016)	Data protection and privacy regulation	Global benchmark for oversight	Insufficient to address issues of dignity and discrimination in defense	Privacy protection alone is not enough
EDPS (2015, 2016)	European ethical initiatives for rights protection	Highlights human rights concerns	Not yet translated into binding policies	Institutional responsibility requires enforcement authority
Cummings (2021)	Embedding institutional mechanisms to reduce risks	Links institutional training to risk reduction	Focuses primarily on military context	Responsibility requires operational implementation tools
Thurnher (2013)	Risks of autonomous weapons dependency	Early legal and security warning	Predominantly diagnostic with limited practical planning	Institutional responsibility necessitates continuous review
Mitchell et al. (2019); Gebru et al. (2018)	Regulatory tools such as Model Cards and Data-sheets	Promote transparency and system disclosure	Not yet widely adopted in defense	Practical tools for accountability and transparency

public awareness of the risks associated with intelligent armament remains limited.

Cummings(89) confirms that embedding such institutional mechanisms reduces risks and promotes responsible use of AI in military operations. Thurnher(4) likewise warns that unchecked reliance on autonomous weapons systems raises complex legal and security challenges that necessitate rigorous institutional review. Additionally, recent studies propose regulatory tools such as *Model Cards* and *Datasheets* to enhance transparency and disclose characteristics of intelligent defense systems(90,91). Table 3 Shows the main institutional and regulatory approaches to AI in defense.

To overcome these gaps, this paper proposes the establishment of new institutional structures as follows:

- National Centers for Responsible Defense AI, tasked with developing binding standards before approving any military AI system.
- Independent Review Committees to assess security and ethical risks—modeled on medical research ethics boards—to reinforce transparency and accountability.
- Mandatory Training Programs for military leaders and AI developers to raise awareness of security and social implications and reduce the likelihood of irresponsible decision-making.

Addressing these risks cannot remain within the realm of theoretical recommendations; it requires a comprehensive institutional and regulatory framework that combines *ex-ante review*, *continuous oversight*, and *periodic evaluation*, grounded in transparency and accountability as fundamental conditions. Accordingly, integrating this dimension with the international and socio-cultural levels represents the most effective pathway to ensuring that defense innovation in the AI era remains responsible and conducive to societal safety and stability.

The analysis across the three levels reveals that achieving responsibility in AI-driven defense innovation demands an integrative approach that

transcends the boundaries of each level in isolation. At the international level, treaties and initiatives seek to establish binding frameworks to prevent arms races and ensure state compliance with humanitarian principles, yet they remain constrained by political interests and power dynamics. The socio-cultural level demonstrates that true legitimacy arises from societal trust and value alignment, and that neglecting cultural context risks ethical fragmentation and normative conflict. Meanwhile, the institutional--regulatory level highlights that legal and ethical frameworks must be operationalized through practical governance mechanisms that guarantee transparency and sustained accountability.

The comparison among these levels shows that the absence of any one dimension creates a gap that undermines responsible AI deployment in defense contexts. Thus, balanced integration across the three levels constitutes the optimal pathway for aligning defense innovation with ethical and humanitarian values while safeguarding societal security and stability.

Conclusion

This study has demonstrated that AI-driven defense innovations generate a set of fundamental risks that cannot be overlooked. First, these innovations may constitute a direct threat to human life, particularly through the proliferation of autonomous weapons systems capable of making lethal decisions beyond human control. Second, the study revealed the potential for AI to be exploited in the Terrorist Exploitation, whether through its use in unlawful operations or as a tool for recruitment, propaganda, and incitement to violence. The third risk lies in the domain of cyber and electronic warfare, where AI technologies open new horizons for large-scale digital attacks that are difficult to predict or contain. Finally, the problem of absent accountability—or what has been termed *responsibility gaps*—emerges, as these systems may produce harmful outcomes without a clearly identifiable agent who can be held justly and transparently accountable.

To address these risks, the study highlights that realizing the principle of responsibility requires an integrated, multi-level approach. At the interna-

tional level, binding treaties and regulatory frameworks are needed to govern the military uses of AI, while also accounting for cultural and religious differences in shaping ethical standards. At the socio-cultural level, engaging local communities and religious institutions in policymaking, strengthening human oversight, and ensuring alignment with shared human values are essential to enhance legitimacy and social trust. At the institutional-regulatory level, specialized oversight bodies—such as independent review boards and national centers for responsible defense AI—must be established, alongside the development of modern transparency tools such as *Datasheets* and *Model Cards*, to ensure continuous accountability and adherence to ethical standards.

Responsibility, as addressed in this study, is not confined to a single dimension but serves as the unifying thread linking society, ethics, and defense innovation. The paper has specifically focused on *negative responsibility*—that is, the accountability of different actors for harms and violations arising from military AI applications—while deliberately excluding positive or forward-looking responsibilities highlighted in other literature.

The findings confirm that ethical values constitute the foundation for building responsibility in confronting the risks of AI-driven defense innovations. At the international level, values such as justice, dignity, transparency, and the protection of human life serve as the bedrock for treaties and conventions regulating these technologies. At the institutional-regulatory level, embedding values into national laws and defense policies ensures that innovations remain subject to a clear ethical framework, preventing impunity. At the socio-

cultural level, respecting religious, cultural, and moral diversity is a prerequisite for public trust and acceptance, ensuring that AI is not perceived as a weapon undermining identity and values but as a tool that can be controlled to serve and protect humanity. Hence, any debate on responsible defense innovation cannot succeed without placing ethical values at the core, guiding policymakers, developers, and societies alike.

The study concludes that addressing these risks is not merely a philosophical debate about the boundaries of responsibility, but a complex practical challenge that depends on the willingness of states and institutions to adopt binding and transparent mechanisms. The greatest obstacle, however, may lie in the military and economic interests of major powers that dominate AI defense innovations, which could obstruct binding international agreements—compounded by a lack of trust between states, disparities in technological capabilities, and resistance from commercial actors unwilling to accept constraints on their interests. Nevertheless, the researcher contends that advancing comprehensive regulatory frameworks and ensuring meaningful global engagement remain the most vital pathways to prevent these innovations from evolving into an existential threat to humanity.

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DIMENSIONES EPISTEMOLÓGICAS PARA UNA BIOÉTICA INFORMADA DE LA DISCAPACIDAD

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Resumen: La relación de la bioética con la discapacidad y su comprensión más allá del saber biomédico dominante ha sido controvertida. Los debates sobre bioética suelen resultar inquietantes para las personas con discapacidad y para los activistas por los derechos de las personas con discapacidad, dados los supuestos opresivos asociados a considerar la discapacidad solamente circunscrita a una definición de una enfermedad que debe curarse. El presente artículo propone algunas dimensiones epistemológicas claves para una bioética informada de la discapacidad. Para este propósito presenta inicialmente las controversias y tensiones en torno a la bioética y la discapacidad para, posteriormente, desarrollar tres dimensiones epistemológicas: una bioética que comprende la discapacidad desde una perspectiva de derechos humanos; una que investiga considerando los estudios sociales y críticos de la discapacidad, y otra que considera para la toma de decisiones las experiencias vividas por las personas con discapacidad.

Palabras clave: bioética, discapacidad, bioética informada de la discapacidad

Epistemological dimensions for informed bioethics of disability

Abstract: The relationship of bioethics with disability and its understanding beyond dominant biomedical knowledge has been controversial. Debates about bioethics are often disturbing for people with disabilities, and for disability rights activists, given the oppressive assumptions associated with considering disability only limited to a definition of an illness, which must be cured. This article proposes some key epistemological dimensions for informed bioethics of disability. For this purpose, it initially presents the controversies and tensions around bioethics and disability, and subsequently develops three epistemological dimensions: bioethics that understands disability from a human rights perspective; bioethics that investigates considering the social and critical studies of disability, and bioethics that considers the experiences lived by people with disabilities in decision-making.

Keywords: bioethics, disability, informed bioethics of disability

Dimensões epistemológicas para uma bioética informada sobre a deficiência

Resumo: A relação da bioética com a deficiência e a sua compreensão para além do conhecimento biomédico convencional tem sido controversa. Os debates sobre bioética são muitas vezes inquietantes para as pessoas com deficiência e para os ativistas dos direitos das pessoas com deficiência, tendo em conta os pressupostos opressivos associados à ideia de que a deficiência se limita apenas à definição de uma doença a curar. Este artigo propõe algumas dimensões epistemológicas fundamentais para uma bioética informada sobre a deficiência. Para o efeito, apresenta inicialmente as controvérsias e tensões em torno da bioética e da deficiência e, em seguida, desenvolve três dimensões epistemológicas: uma bioética que compreenda a deficiência numa perspetiva de direitos humanos; uma bioética que investigue a deficiência numa perspetiva de estudos sociais e críticos sobre a deficiência; e uma bioética que considere as experiências vividas pelas pessoas com deficiência na tomada de decisões.

Palavras-chave: bioética, deficiência, bioética informada sobre a deficiência

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Introducción

En la bioética occidental los principios éticos interrelacionados de respeto por la autonomía, beneficencia, no maleficencia y justicia han sido generalmente aceptados para determinar las acciones, prácticas y políticas correctas en varios escenarios de atención médica, desde las relaciones terapéuticas hasta las decisiones reproductivas y la atención al final de la vida, la investigación clínica y el tratamiento médico, así como las decisiones políticas y de financiación más amplias(1). Los principios pueden ser descritos de la siguiente manera:

No obstante, a estos principios morales generales, las discusiones sobre los dilemas bioéticos que utilizan estos principios a menudo privilegian las posiciones de las personas sin discapacidad, descartando las perspectivas sociales y críticas de la discapacidad y reforzando los supuestos opresivos asociados a considerar la discapacidad solamente circunscrita a una definición de enfermedad, que en cuanto tal debe curarse o sanarse. Los estudios que apuntan a la proposición de una bioética de la discapacidad y que han surgido en la última década han indicado cómo en los casos en donde media el criterio bioético cuando se trata de la discapacidad se han cometido “errores”(2) que guardan relación con las connotaciones que la discapacidad tiene en el espacio médico. Hernández y Revuelta (2024) sugieren el concepto de “injusticias epistémicas normalizadas” para hacer referencia a un sistema hermenéutico capacitista, que restringe la agencia de las personas con discapacidad en cualquier ámbito social, al comprometer con nociones opresivas los recursos hermenéuticos colectivos en cada sociedad(3). La bioética no queda exenta de este sistema, mucho más cuando lo que está a la base de sus investigaciones en torno a la discapacidad es justamente el discurso médico dominante, responsable del establecimiento de los estándares de “normalidad”(4).

A pesar de sus orígenes como un campo fuera de la medicina y tener una postura crítica con las prácticas médicas prevalecientes, la bioética en la actualidad está profundamente arraigada en las facultades de medicina y los hospitales. Los bioeticistas son médicos y los médicos son “éticos”. Inmersos en la cultura de la medicina, los bioeti-

cistas confían instintivamente en sus colegas clínicos para hacer lo correcto o, en términos de bioética, para ejercer el criterio médico profesional(5).

El presente artículo propone algunas dimensiones epistemológicas claves para una bioética informada de la discapacidad. Para este propósito, presenta inicialmente las controversias y tensiones en torno a la bioética y la discapacidad y, posteriormente, desarrolla tres dimensiones epistemológicas: una bioética que comprende la discapacidad desde una perspectiva de derechos humanos; una que investiga considerando los estudios sociales y críticos de la discapacidad, y otra que considera para la toma de decisiones las experiencias vividas por las personas con discapacidad. Estas dimensiones del quehacer científico en el campo resultan claves para una bioética que pueda comprender las implicancias sociales de la toma de decisiones biomédicas desde una perspectiva relacional, contextualizada y humana.

Bioética y discapacidad: controversias y tensiones

La relación de la bioética con la discapacidad y su comprensión más allá del saber biomédico dominante ha sido polémica(6). Vehmas afirma que “la relación entre bioética y discapacidad se ha centrado tradicionalmente en el asesinato, (...) la literatura bioética ha discutido principalmente la discapacidad como un factor que justifica la permisibilidad moral del asesinato activo o pasivo de personas con discapacidad, o la prevención de la existencia de dichas personas”(7:146), incluso se considera “el activismo en discapacidad como fundamentalmente opuesto a los objetivos de la bioética”(8:336), observándola con “desdén”(9:166). En consecuencia, los debates sobre bioética suelen resultar inquietantes para las personas con discapacidad, dada la forma en que suponen que vivir con una discapacidad es inevitablemente malo, o mucho peor que vivir una vida normal(7). Alice Ouetlette, autora clave en la propuesta de una bioética de la discapacidad, refiere que “las personas con discapacidad se sienten devaluadas en el ámbito de la atención médica, se sienten amenazadas, incomprendidas, insultadas, marginadas y asustadas. Desde la perspectiva de la discapacidad, el ámbito de la atención sanitaria es un lugar peligroso y difícil”(5:320).

Se ha reconocido que los bioeticistas que no hacen bioética de la discapacidad comparten cuatro tipos de supuestos sobre la discapacidad. En primer lugar, sus posiciones tienden a estar en consonancia con el modelo médico de discapacidad, que la conceptualiza de forma restringida y únicamente a nivel del cuerpo de un individuo; en segundo lugar, los especialistas en bioética respaldan implícita o explícitamente puntos de vista de la discapacidad como diferencias negativas, que sostienen que la discapacidad inevitablemente reduce la calidad de vida y lo haría incluso aparte de la eliminación de factores sociales, tales como estigmatización, pobreza inducida e inaccesibilidad; en tercer lugar, los argumentos de los bioeticistas involucran determinismo biológico; y en cuarto lugar, los especialistas en bioética suponen que las experiencias de las personas con discapacidad se pueden comparar con las experiencias de las personas sin discapacidad y, por lo tanto, no recurren regularmente a pruebas basadas en las experiencias vividas por personas con discapacidad(10).

Tomando en consideración estos supuestos, el enfoque tradicional de la bioética sobre la discapacidad se ha considerado problemático, porque tiende a aceptar acríticamente la comprensión médica de la discapacidad como una desviación de las normas biológicas de forma o función, más que como el resultado de una interacción compleja entre el cuerpo, la cultura y el medio ambiente; se evidencia además un sesgo teórico de la bioética hacia el universalismo, que la lleva a homogeneizar la diversidad de la “encarnación no normativa”, es decir, a teorizar en torno a una idea abstracta de “discapacidad”, en lugar de deficiencias específicas, y como disciplina también muestra una falta integral de conciencia sobre los conceptos y sensibilidades de los derechos de las personas con discapacidad(11).

El debate apunta entonces a una comprensión superficial que puede derivar en un accionar perjudicial para los intereses de las personas con discapacidad y conducir a debates bioéticos que entran en conflicto con las experiencias vividas, las perspectivas y los intereses de estos grupos. Estos debates no tienen en cuenta la problemática relación histórica entre la práctica médica y la discapacidad, hecho que trajo consigo la institu-

cionalización y la experimentación en sus cuerpos sin consentimiento. A su vez ignoran las fuerzas sociales y culturales que oprimen a las personas con discapacidad. Como bien explica Garland Thompson, la representación estructura la realidad(12) y la no consideración de estos hechos dificulta que el debate y prácticas tiendan hacia decisiones biomédicas en las que la persona se considere en una diversidad más amplia. Si la atención debe estar centrada en la persona, esta centralidad debería ser más sensible a las múltiples formas en las que se constituyen los sujetos.

A pesar de estas controversias y tensiones, también pueden hallarse posturas diferentes respecto de la bioética. Ouellette plantea que es posible encontrar una empresa que implica un debate reflexivo, a menudo vigoroso, y un análisis cuidadoso de problemas complejos sobre la mejor manera de garantizar el respeto a la elección individual, prevenir el sufrimiento y asignar justamente recursos escasos(5). Esta autora agrega que pueden encontrarse puntos en común entre los expertos en discapacidad y los bioeticistas: “comparten un interés común en promover un sistema médico bueno y justo en el que todas las personas sean tratadas con respeto. Tanto los bioéticos como los expertos en discapacidad están a favor de una asignación justa, no discriminatoria y no arbitraria de recursos escasos. Ambos grupos también comparten el compromiso de garantizar la toma de decisiones médicas informadas por y para las personas con discapacidad. Los defensores de la discapacidad también comparten con los bioéticos el interés de permitir que las personas con discapacidad tomen decisiones autónomas y dirijan sus propias vidas”(5:330). Sin embargo, mientras la bioética siga siendo percibida como insensible o indiferente ante las preocupaciones de las personas con discapacidad, y no esté informada de perspectivas que ponderen los derechos humanos y miradas sociales complejas que implica pensar en los lugares de enunciación de los sujetos, mucho más si han sido tradicionalmente marginados, las perspectivas de reconciliación seguirán siendo escasas(5).

Dimensiones epistemológicas para una bioética informada de la discapacidad

En este apartado interesa considerar tres dimen-

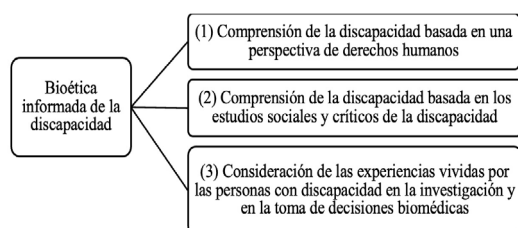
siones epistemológicas concernientes al quehacer bioético cuando se trata con personas con discapacidad. Estas dimensiones resultan claves para una comprensión bioética informada, que no solo considere la mirada médica de la discapacidad, sino que tenga en cuenta cómo esa mirada de “sujetos enfermos que deben curarse” restringe el espacio de toma de decisiones e invisibiliza los impactos sociales que, sobre las personas sometidas a un tratamiento o intervención médica y sus familiares, pueden tener.

Las experiencias de vida de las personas eventualmente contradicen el imaginario colectivo dominante que considera cierta estabilidad predictiva y controlable del cuerpo. Este imaginario colectivo ha generado una respuesta específica convencional a la discapacidad en los espacios médicos, que consiste en cambiar a la persona a través de la tecnología, en lugar de cambiar el entorno para acomodarlo a una gama más amplia de formas y funciones humanas(13). En consecuencia, no es posible establecer un estándar, aun cuando este estándar es el que ha regido por muchos años las interacciones sociales y médicas en torno a las personas con discapacidad. Una bioética informada de la discapacidad debe partir por reconocer los etiquetamientos que derivan de un saber experto que, con argumentos basados en condiciones biológicas y médicas, ha marginado a ciertos grupos sociales. La variación corporal, explicada como “anomalía”, se ha traducido socialmente en un “otro” anómalo, riesgoso o con el que se tiene que ser solidario porque tiene una vida desdichada, es enfermo o inferior a aquellos “normales”. Esta mirada opresiva es la responsable de las anuencias del saber profesional médico para la intervención corporal o la toma de decisiones en torno a estas “anomalías”, que no serían las mismas que se emplearían para una persona “normal” y considerada “capaz”.

Una bioética informada de la discapacidad debe considerar las significaciones sociales asociadas a cuerpos específicos, no ajustados al “ideal normativo”, y para ello requiere contar con recursos hermenéuticos contra capacitistas que permitan generar una justicia epistémica(3), a la vez que deconstruir ese imaginario de “cuerpo defectuoso” que debe mejorarse o sanarse. Esta bioética es posible si se tiene en cuenta al menos las siguientes

tres dimensiones que involucran el posicionamiento teórico-político, el lugar de los sujetos con discapacidad en los intercambios biomédicos, y sus experiencias y vivencias en salud atravesadas por la ideología de la “normalidad” y el “capacitismo” que estandariza y homogeneiza los cuerpos, produciendo los marcos hermenéuticos por medio de los cuales comprendemos, evaluamos o diagnosticamos la vida y la salud de los otros.

Figura 1. Tres dimensiones epistemológicas para una bioética informada de la discapacidad



Fuente: Elaboración propia a partir de (5,10,11,14).

Estas tres dimensiones permiten el desarrollo de una bioética crítica y atenta a las narraciones de sentido común en torno a la discapacidad, a la vez que la teoría y la práctica quedan sustentadas en los estudios críticos sobre discapacidad, con énfasis en el testimonio y el trabajo de las personas que la viven. Este lente consciente e informado de la discapacidad implica una cuidadosa consideración de a dónde se recurre para obtener datos; cómo se interpretan y, de otro modo, cómo se analizan reflexivamente esos datos; quién está en la mesa y quién es llevado a ella respecto de la toma de decisiones, ya sea a nivel básico o clínico, y los valores sobre los cuales se ancla la investigación(10).

Comprensión de la discapacidad basada en una perspectiva de derechos humanos

Alicia Ouellette propone que, para desarrollar una bioética consciente y conocedora del hecho de la discapacidad, que trabaje para y con las personas con discapacidad, es necesario basarla en la Convención por los Derechos de las Personas con discapacidad. Dada la importancia de los principios morales en la bioética, un punto de partida

natural para construir una bioética consciente de la discapacidad es considerar la incorporación de los principios centrales de la Convención al trabajo de los bioeticistas.

Como se enuncia en la Convención de las Naciones Unidas sobre los Derechos de las Personas con Discapacidad, esos principios son: “(a) Respeto por la dignidad inherente, la autonomía individual, incluida la libertad de tomar sus propias decisiones, y la independencia de las personas; b) no discriminación; (c) participación e inclusión plenas y efectivas en la sociedad; d) respeto por la diferencia y aceptación de las personas con discapacidad como parte de la diversidad humana y la humanidad; e) igualdad de oportunidades; f) accesibilidad; g) igualdad entre hombres y mujeres; y (h) respeto por la evolución de las capacidades de los niños con discapacidad y respeto por el derecho de los niños con discapacidad a preservar sus identidades. La Convención utiliza estos principios para derivar obligaciones generales y normas aplicables a los Estados partes” (5).

Por otro lado, la inclusión de los principios que establece la Convención en las discusiones de la bioética podría potenciarse si se consideran las perspectivas de los teóricos críticos de la discapacidad. Conciernen a la bioética trabajar con expertos en discapacidad para eliminar ese sesgo y comprender que la historia de la discapacidad no tiene por qué ser la historia de la tragedia y que

las suposiciones sesgadas y refutadas sobre la vida con discapacidad están en juego en la toma de decisiones médicas(10).

Comprensión de la discapacidad basada en los estudios sociales y críticos de la discapacidad

La discapacidad es una categoría que se ha entendido normativamente a través del discurso médico. La medicina ha tendido a desmitificar y naturalizar la anomalía somática, eliminando cualquier significado sobrenatural o moral, y ha caracterizado la variación física únicamente como un asunto que la ciencia puede investigar e intentar remediar. En la medida en que la discapacidad se expresa a través del conocimiento médico, se circunscribe a leerse únicamente a través del lenguaje biológico, genético, hormonal, neurológico y fisiológico(15). Los estudios sociales de la discapacidad han surgido en respuesta a este discurso autorizado de medicalización y han generado un cambio significativo en el horizonte de reconocimiento a estos grupos. Estos estudios han impulsado la definición de la discapacidad no como un “defecto físico”, sino como una forma de comprender estructuras opresivas. De este modo, la discapacidad se ha convertido en un sistema de representación más que un problema médico o una desgracia personal asociada a un cuerpo. En consecuencia, una discusión sociopolítica en torno a la realidad de las personas con discapacidad se ha potenciado para observar la vulneración de

Tabla 1. Elementos interconectados en la competencia cultural de la discapacidad

Componentes	Dimensiones que involucra
1) Toma de decisiones biomédicas	Prácticas, políticas, leyes, educación y actitudes en relación con la discapacidad
2) Cultura e historia de la discapacidad	Conciencia, apoyo, desarrollo y promoción de la historia, la cultura, la cultura material y las artes de la discapacidad
3) Tecnología y diseño accesibles	Diseño, desarrollo y promoción de tecnología accesible basados en el usuario como condición para la calidad de vida de las personas con discapacidad.
4) Legislación sobre discapacidad y justicia social	Conocimiento y concientización de derechos legales, obligaciones, protecciones y beneficios de las personas con discapacidad.
5) Investigación de la competencia cultural de la discapacidad	Investigación en torno a la calidad de vida, el mantenimiento de la dignidad, el acceso y la autodeterminación.

Fuente: Construcción propia partir de(17).

derechos, la invisibilización y las diversas formas de opresión a las que se somete a estos grupos(16).

En este sentido, Garland-Thompson sugiere dotar a los bioeticistas de lo que denomina “competencia cultural de la discapacidad”, que alude justamente a reconocer e incorporar el conocimiento en torno a las connotaciones sociales de la discapacidad. Para esta autora, “la competencia cultural de la discapacidad es un conjunto de habilidades o un conjunto de herramientas que todos necesitarán para navegar por la vida e implementar las promesas y obligaciones de las sociedades democráticas igualitarias”(17:332), interpretese también los derechos consagrados en la Convención. Esta competencia cultural involucra cinco elementos interconectados:

La discapacidad puede hacer que el trabajo de un bioético sea más útil, revelador, original y necesario. Pero las formas en que la discapacidad marca la diferencia son complejas, porque la discapacidad es un concepto escalar y multidimensional, que depende en gran medida del contexto más amplio. La experiencia de ser una persona con discapacidad es multifacética. Puede deberse a tener un diagnóstico particular o una limitación funcional consistente en no poder caminar ni oír bien. Puede que se trate de las barreras sociales a las que nos enfrentamos: el circuito auditivo que no funciona, la falta de rampa o ascensor. Puede que se trate de la falta de oportunidades sociales: la falta de seguro médico o de empleo. La experiencia de la discapacidad es el resultado de la interacción entre la persona con la condición de salud y el contexto social y cultural más amplio(18). Estas situaciones deben ser comprendidas por los bioeticistas en términos de “conciencia de la discapacidad”, como menciona Ouellette, reconociendo cuándo y cómo las percepciones sociales negativas sobre la discapacidad se infiltran en las decisiones médicas o en la formulación de políticas, o a la manera de Garland Thomson, como “competencia cultural” de la discapacidad. Ambas autoras aluden a la necesidad de generar prácticas informadas por la investigación y la consideración de la experiencia de las personas con discapacidad en primer lugar.

El objetivo apropiado entonces de la bioética de la discapacidad debe ser fortalecer los aspectos

culturales, políticos, institucionales y de entorno material en el que las personas con discapacidad puedan prosperar más eficazmente. Esta definición saca tanto la discapacidad como la bioética de un contexto principalmente médico o sanitario para expandir sus dominios a entornos materiales, instituciones cívicas, estructuras culturales e interacciones interpersonales(17).

Por otro lado, reconocer el poder distorsionador de la injusticia epistémica es de crucial importancia para la bioética de la discapacidad. Una de las funciones principales de la bioética es evaluar la permisibilidad ética de nuevas intervenciones y políticas de atención de salud. La discusión sobre la injusticia epistémica en los espacios de atención en salud sugiere que no es seguro asumir que los recursos de los que se valen los bioeticistas para hacer tales evaluaciones están a la altura del trabajo. De hecho, bioeticistas feministas han identificado que el conocimiento empírico y experiencial de las discapacidades que la bioética aporta a sus deliberaciones es inadecuado(6,19).

Considerar las experiencias vividas por las personas con discapacidad

Una bioética que incorpore el respeto por la diferencia y la aceptación de las personas con discapacidad como principio rector probablemente tendrá un compromiso más amplio que solo con otros académicos en el campo. Se comprometerá, ya sea como discurso académico o aplicación práctica, a refutar los argumentos que no respetan el valor de las personas debido a su condición de discapacidad. Pero incluso una bioética estrictamente interpretada como comprometida con la búsqueda del conocimiento y la comprensión con integridad se beneficiará al luchar con la evidencia de que las personas con discapacidad de manera persistente experimentan una calidad de vida buena o excelente, incluso cuando observadores desinformados puedan predecir lo contrario. La clave para la aplicación del principio de respeto en bioética es el conocimiento y la validación de las múltiples experiencias de discapacidad y el desarrollo de un debate inclusivo y bien informado sobre la vida con discapacidad(5).

Una bioética de la discapacidad debe implicar entonces más que simplemente prestar atención a

ciertos focos de investigación empírica, la adopción activa y la integración del análisis, la comprensión y la interpretación de las experiencias vividas por las personas con discapacidad(10). El campo de la bioética puede mejorar si abandona las generalizaciones sobre quiénes son las personas con discapacidad y cómo actúan, presentadas por narrativas dominantes opresivas, en favor de autodescripciones más matizadas que ofrecen las historias alternativas de las propias personas con discapacidad. Al desafiar estas narrativas maestras opresivas que limitan y distorsionan el significado social de la discapacidad, el activismo en materia de discapacidad puede mejorar la bioética dominante(8). Cuando a alguien se le presenta un argumento que se basa en premisas que contradicen ciertas narrativas ampliamente aceptadas, es probable que ese argumento sea descartado por absurdo. Esto le sucede regularmente a personas que ocupan posiciones sociales subordinadas, simplemente porque existe un sistema hermenéutico construido desde una posición social dominante: la “normalidad”. En consecuencia, muchas de las desventajas de la discapacidad son producidas por relaciones de poder opresivas que devienen de un capacitismo estructural(8) o de un sistema hermenéutico capacitista al que los grupos tradicionalmente subordinados deben “resistir”(20).

Los profesionales deben volverse expertos en los recursos hermenéuticos de las comunidades de personas con discapacidad y otras comunidades marginadas; y los médicos tienen la responsabilidad de reconocer la autoridad de las personas con discapacidad como expertos en sus propias vidas y comunidades, y de alzar sus voces. La medicina se ocupa de los procesos biológicos, no de los procesos de creación de significado de la vida humana tal como se vive realmente. El significado de una parálisis cerebral, por ejemplo, no se encuentra en los libros de texto de medicina: se encuentra escuchando a quienes viven con parálisis cerebral y a sus familiares(21).

Conclusiones

El presente artículo ha tenido como propósito realizar una contribución al campo de la bioética, y en particular a las discusiones epistemológicas en torno a una bioética de la discapacidad. Hemos propuesto tres dimensiones epistemológicas que,

a nuestro juicio, resultan claves para una bioética informada de la discapacidad. En el tránsito hacia las dimensiones hemos indicado importantes desencuentros entre activistas, expertos en discapacidad y bioéticos que propician un ambiente de desconfianza, ruptura y miedo de parte de las personas con discapacidad.

Esta situación ha sido abordada en las dos últimas décadas de forma significativa, y en esta producción científica es posible reconocer algunas de las dimensiones epistemológicas que este trabajo presenta, y que tributan a una comprensión de la discapacidad que escapa al discurso médico capacitista, para situarse desde una mirada social y crítica que intenta brindar el marco para comprender las experiencias de las personas con discapacidad como diferenciadas y en ningún caso interpretables a partir de modelos médicos tradicionales de comprensión del bienestar y la buena vida, asentados en la “normalidad” como ideología opresiva que mina los recursos hermenéuticos colectivos.

Considerar la discapacidad desde una perspectiva de derechos humanos habilita discusiones relevantes sobre las connotaciones diferenciadas que debe tener la bioética cuando investigue o tome decisiones en torno a la vida y el uso de ciertos procedimientos biomédicos con personas con discapacidad. Por su parte, tener en cuenta el saber experto que emana de los estudios sociales y críticos de la discapacidad permite comprender el impacto social que el diagnóstico y el tratamiento médico o discursivo del personal de salud hacia los pacientes tiene en la vida de los sujetos y sus familias. Por último, considerar las experiencias de las personas con discapacidad como válidas evita la injusticia epistémica que se produce en intercambios médicos en donde solo se escucha la voz del profesional de la salud.

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THE ETHICAL PRINCIPLE OF RISK GOVERNANCE: ANALYSIS OF THE DEVELOPMENT OF THE PRECAUTIONARY PRINCIPLE

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Abstract: Modern society needs to be vigilant and respond promptly to risks. The emergence of uncertainties not only may increase the probability of risks occurring but also may exacerbate their severity. Therefore, what ethical principle should be relied on to deal with risks characterized by uncertainty has become a problem to be solved. The precautionary principle is an important ethical principle for addressing and resolving risks with uncertain features. This article aims to explain the changes of the precautionary principle in risk governance from its origin, the expansion of its geographical scope, and the increase in its application fields; and focuses on demonstrating the continuous improvement of the precautionary principle in risk governance through the transformation from the weak precautionary principle governance model with limited effectiveness to the strong precautionary principle governance model with high effectiveness.

Keywords: risks, uncertainty, precautionary principle, ethical governance

El principio ético de la gobernanza del Riesgo. Análisis de la evolución del principio de precaución

Resumen: La sociedad moderna necesita estar alerta y responder con prontitud a los riesgos. La aparición de incertidumbres no solo puede aumentar la probabilidad de que ocurran, sino también que se agraven. Por lo tanto, “qué principio ético debe aplicarse para hacer frente a los riesgos caracterizados por la incertidumbre” se ha convertido en un problema que hay que resolver. El principio de precaución es un principio ético fundamental para abordar y resolver los riesgos con características inciertas. El presente artículo tiene por objeto explicar los cambios del principio de precaución en la gobernanza del riesgo desde su origen, la ampliación de su ámbito geográfico y el aumento de sus campos de aplicación, y se centra en demostrar la mejora continua del principio de precaución en la gobernanza del riesgo, a través de la transformación del modelo de gobernanza del principio de precaución débil, con una eficacia limitada, al modelo de gobernanza del principio de precaución fuerte, con una alta eficacia.

Palabras clave: riesgos, incertidumbre, principio de precaución, gobernanza ética

O princípio ético da governança de riscos: Análise do desenvolvimento do princípio da precaução

Resumo: A sociedade moderna necessita ser vigilante e responder prontamente a riscos. A emergência de incertezas não somente aumenta a probabilidade de riscos ocorrerem como também podem exacerbar sua gravidade. Assim, qual princípio ético deve ser adotado para lidar com riscos caracterizados pela incerteza, tornou-se um problema a ser resolvido. O princípio da precaução é um princípio ético importante para abordar e resolver riscos com características incertas. Esse artigo objetiva expor as mudanças do princípio da precaução na governança de riscos desde sua origem, a expansão de sua abrangência geográfica e ao aumento em seus campos de aplicação; e concentra-se em demonstrar a contínua melhora do princípio da precaução na governança de riscos através da transformação de um fraco modelo de governança baseado no princípio da precaução, com eficácia limitada, para um forte modelo de governança baseado no princípio da precaução, com alta eficácia.

Palavras chave: riscos, incerteza, princípio da precaução, governança ética

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Introduction

Risks mainly refer to undesirable events that may or may not occur(1). Among these, the risks that may lead to a large number of casualties, significant economic losses, or extensive environmental damage deserve particular attention. With the rapid development of technology, especially the emergence of “technological convergence”(2) and the appearance of “uncertain” emerging technologies(3,4) with the potential to create new industries or transform existing ones(5), the risks and their potential negative impacts have become increasingly alarming.

The precautionary principle is an ethical principle that emerges along with risks. Its fundamental proposition is: In the presence of certain scientific uncertainties, precautionary measures should be taken. Its core demand is to avoid potential risks from evolving into actual harm in the future. We need to prevent the occurrence of harm from the very beginning. This principle can change along with the changes in risks and the demands for risk governance.

Due to the insufficient understanding of the concept of the precautionary principle by the public, some people have misunderstood it, questioning its effectiveness and opposing its application. This may delay the governance process, leading to delayed and flawed governance. Therefore, this article examines the origin of the precautionary principle, its application in different regions, its application in different fields, and the changes in its effectiveness, in order to enable people to understand how the precautionary principle continuously improves itself and functions in a risk society.

1. The origin of the precautionary principle

The origin of the precautionary principle can be traced back to the “no harm” principle in the Hippocratic Oath(6). In the 1950s, some people in the United States used a similar view to the precautionary principle to oppose fluoridation of water, and in the 1960s, others used similar arguments to oppose nuclear energy; they believed that high doses of fluoride or nuclear radiation had known adverse effects, and thus, if not used properly, could cause widespread harm(7).

The concept of the precautionary principle first emerged in a draft German bill aimed at ensuring clean air in 1970 (the bill was passed in 1974), and was then known as “Vorsorgeprinzip”. It was intended to reduce and limit environmental risks from a safety perspective or to protect and improve natural conditions by predicting future environmental conditions(8). The country’s 1976 Environmental Report and 1986 Environmental Precautionary Guidelines also adopted the precautionary principle as the guiding principle for its environmental policies(9). It can be said that Germany’s environmental policies have provided a relatively specific and comprehensive elaboration of the precautionary principle. By “relatively specific”, it means that the requirements of the precautionary principle are relatively clear. This principle divides human actions into those that cause harm and those that cause risks. For actions that cause harm, the government should take all measures to prevent them; for actions that cause risks, the government should conduct risk analysis and order precautionary measures when deemed appropriate. This principle provides a legitimate reason for the German government to intervene in the daily lives of states and citizens under the name of good governance, as well as to plan the economy, technology, morality, and society(10,11). By “relatively comprehensive”, it means that the content of the precautionary principle covers responsibility to future generations, comprehensive and simultaneous research, action before scientific conclusions, and the burden of preventing harm through technological progress. The principle states that “responsibility to future generations means protecting the natural basis of life and avoiding irreversible damage such as forest decline”, so “harm to the natural world (that is, the world on which we all depend for survival) should be avoided in advance based on opportunities and possibilities; to “discover dangers to health and the environment as early as possible through comprehensive and simultaneous research, especially research on cause and effect”; to “take action before scientific conclusions are reached”; to “develop technological processes in all economic sectors that can significantly reduce the environmental burden (especially those caused by the introduction of harmful substances)”(12).

Since the 1980s, the precautionary principle has gradually become an important component of governance policies. The process of continuously enriching the concept and application scope of the precautionary principle at successive “International Conferences on the Protection of the North Sea” marked the beginning of its gradual introduction to the international stage of risk governance. The “Declaration of the International Conference on the Protection of the North Sea” formed at the first “International Conference on the Protection of the North Sea” held in Bremen in 1984 proposed that “for the protection of the North Sea, precautionary measures to control air quality through reducing emissions at the source should be determined based on the best available technology” and “detailed plans should be developed to take precautionary measures in response to emergencies and accidents”, which was the embryonic form of the precautionary principle in international agreements(13). At the “Second International Conference on the Protection of the North Sea” held in London in 1987, the “Ministerial Declaration” proposed the “principle of precautionary action” or “precautionary approach” under the name of the precautionary principle; the governance characteristics of the precautionary principle, which limits harm or negative impacts from the source regardless of whether there is sufficient scientific evidence to prove the causal relationship between actions and hazards, and the construction of a hazardous substance handling approach with the characteristics of a precautionary path, were clarified(14). At the “Ministerial Declaration of the Third International Conference on the Protection of the North Sea” held in The Hague in 1990, the term “precautionary principle” first appeared in the series of North Sea protection conferences(15). In 1995, at the “Fourth International Conference on the Protection of the North Sea”, the “Esbjerg Declaration” formed there made the precautionary principle the guiding principle for achieving the goal of ensuring the sustainable, sound and healthy state of the North Sea ecosystem, further enhancing the principle’s status in environmental risk governance(16). In 2002, the “Bergen Declaration” formed at the “Fifth International Conference on the Protection of the North Sea” initially expanded the application scope of the

precautionary principle to the field of genetically modified organisms, and focused on addressing and responding to the “inherent, potentially serious, irreversible and transboundary impacts” resulting from the release of genetically modified organisms, thereby “ensuring that the cultivation of genetically modified marine organisms is restricted within a safe range”(17).

2. Expansion of geographical scope

The Convention for the Protection of the Marine Environment of the North-East Atlantic, also known as the OSPAR Convention, which was formed at the Ministerial Meeting of the Oslo and Paris Commissions, has a broader geographical scope than the previous International Conferences for the Protection of the North Sea, but the applicable fields are similar. Therefore, there is a certain degree of mutual reference in the understanding and application of the precautionary principle between the two. For instance, the OSPAR Convention defines the precautionary principle as: “When there are reasonable grounds for concern that the introduction of substances or energy into the marine environment, directly or indirectly, may cause harm to human health, damage biological resources and marine ecosystems, deteriorate environmental quality or interfere with legitimate uses of the sea, precautionary measures should be taken even in the absence of conclusive evidence of a causal relationship between the input and the effect.” This is similar to the definition of the precautionary principle in the Ministerial Declaration of the Second International Conference for the Protection of the North Sea(18). The Treaty on European Union, also known as the Maastricht Treaty, has expanded the geographical influence of the precautionary principle from the North Sea and the North-East Atlantic to the entire European Union, and it can be applied in fields such as the environment, public health, and consumer protection(19). It also combines the goal of “a high level of protection” and the consideration of “the diversity of situations in different regions within the Community” with the precautionary principle(20).

Apart from Europe, other countries and regions around the world have also adopted the precautionary principle as an important principle of

national or regional policies, further expanding its influence. For instance, the Bamako Convention on the Ban of the Import into Africa and the Control of Transboundary Movement and Management of Hazardous Wastes within Africa, or simply the Bamako Convention, marks an important beginning for many African countries to apply the precautionary principle to address the threat of hazardous waste. The convention recognizes that the volume of hazardous waste is constantly increasing and that its complexity poses an increasingly serious threat to human health and the environment. Therefore, it proposes that "Parties shall strive to adopt and implement precautionary approaches to address pollution problems, including but not limited to preventing the release of substances that may cause harm to human health or the environment before scientific evidence of such harm is obtained" and "Parties shall cooperate and take appropriate measures to implement the precautionary principle through the application of clean production methods to prevent pollution, rather than pursuing methods that allow emissions based on the assumption of environmental self-purification capacity", and urges the contracting parties to effectively manage and restrict the cross-border transportation of hazardous waste in Africa(21). In the United States, precautionary thinking is also at play, with severe and irreversible harm being prioritized for precaution. For example, the "Precautionary Principle Ordinance" proposed by the San Francisco Board of Supervisors - which later evolved into "The San Francisco Precautionary Principle" in the San Francisco Environment Code(22): "In the presence of a threat of serious or irreversible harm to human health or the natural environment, the lack of full scientific certainty about cause and effect shall not be used by the City as a reason for postponing cost-effective measures to prevent environmental degradation or protect the health of its citizens"(23). Since then, San Francisco has become the first local government in the United States to clarify and implement the precautionary principle, providing a new path for the city to formulate and implement laws and policies related to health and the environment.

The Rio Declaration on Environment and Development, also known as the Rio Declaration,

for the first time expanded the geographical scope of the precautionary principle to the global level, making it a universal principle. Moreover, the declaration set "the threat of serious or irreversible harm"(24) as the premise for the widespread adoption of precautionary measures, enabling countries to protect human health and the ecological environment while also considering prudent development. The United Nations Framework Convention on Climate Change and the Convention on Biological Diversity, both adopted in the same year, also contributed to the globalization of the precautionary principle. The United Nations Framework Convention on Climate Change stipulates that "each Party shall take precautionary measures to predict, prevent or minimize the causes of climate change and mitigate its adverse effects."(25) Although the Convention on Biological Diversity does not directly use the term "precautionary principle," its content reflects the precautionary thinking that measures should be taken to avoid significant reduction or loss of biodiversity in the face of serious and irreversible harm with scientific uncertainty(26).

3. Expansion of Applicable Fields

The above-mentioned countries, regions and international treaties, while introducing the development of the precautionary principle, focus on demonstrating its continuous expansion in geographical scope and mainly concentrate on the environmental field (a considerable part only incidentally touches upon public health, genetically modified organisms, consumer protection and other fields), while the following policies and treaties show that the precautionary principle plays a major role in more fields.

The Cartagena Protocol on Biosafety, by emphasizing that the contracting parties should be aware that "modern biotechnology is developing rapidly, and the public is increasingly concerned about its potential adverse effects on biodiversity, as well as the risks it poses to human health" and that "if modern biotechnology is developed and utilized under adequate safeguards for the environment and human health, it will have great potential for human well-being", thus "reaffirms the precautionary approach as set out in the Rio Declaration on Environment and Development",

has thoroughly extended the focus and application of the precautionary principle to the field of biotechnology. At the same time, the Cartagena Protocol on Biosafety, based on the precautionary principle, “addresses issues such as biodiversity and biosafety (protecting human health and the environment from potential adverse effects of modern biotechnology products), and provides a comprehensive and holistic approach for the conservation of biodiversity, the sustainable use of natural resources, and the fair and equitable sharing of benefits arising from the utilization of genetic resources”(27), significantly enhancing the status of the precautionary principle in the governance of biotechnology. Additionally, the Stockholm Convention on Persistent Organic Pollutants, which aims to protect human health and the environment from chemical substances and strengthen the management of chemicals, incorporates chemicals, especially toxic and harmful ones, into the application objects of the precautionary principle(28). Similar to the Cartagena Protocol on Biosafety, this convention is also influenced by the Rio Declaration, taking the precautionary principle in the Rio Declaration as the benchmark for chemical governance. It is particularly worth noting that this convention is one of the earlier international treaties to link scientific uncertainty with the precautionary principle.

If the Rio Declaration made the precautionary principle a universal principle, then the report named “The Precautionary Principle” formulated by the World Commission on the Ethics of Scientific Knowledge and Technology of UNESCO has made it a truly multi-field universal principle. The report states that “when human activities may cause morally unacceptable harm, and such harm is scientifically possible but not yet certain, actions should be taken to avoid or mitigate such harm; morally unacceptable harm refers to harm to humans or the environment that threatens human life or health, or is serious and actually irreversible, or is unfair to the present or future generations, or is imposed without fully considering the human rights of those affected”(29). This “working definition” creatively shifts the trigger for precautionary measures from direct harm or harmful effects to morally unacceptable harm. This not only more closely links the precaution-

ary principle with ethics but also constrains the triggering and application of restrictions and bans in precautionary measures within a reasonable range, thereby facilitating scientific and technological development and social progress.

Since the promulgation of the above-mentioned treaty until today, there have been countless declarations, guidelines, policies and regulations applying the precautionary principle to specific fields such as medical research and development, infectious disease prevention and control, artificial intelligence, autonomous driving, and synthetic biology, making the precautionary principle a significant ethical principle in the world and making precautionary thinking and approaches generally the basis and starting point of policymaking. However, the specific expressions of the precautionary principle in various policies are diverse and complex, sometimes making it difficult for people to clearly understand it and even leading to misunderstandings. Therefore, it is necessary to analyze them by type and weigh them in application.

4. Changes in governance models

4.1 Limited governance of the weak precautionary principle

The weak precautionary principle is an early version of the precautionary principle (it even predates the prior principle and became the main target of criticism for the prior principle). Although this version is still occasionally invoked today due to its certain rationality, its limited governance effectiveness has hindered its application in the governance of emerging technology risks.

4.1.1 Pay attention to potential serious and/or irreversible risks

One of the characteristics of the weak precautionary principle is its focus on potential serious and/or irreversible risks. This is exemplified by the precautionary principle mentioned in the “Meeting on Sustainable Development” held by the Economic Commission for Europe (ECE). It states: “To achieve sustainable development, policies must be based on the precautionary principle. Environmental measures must anticipate,

prevent, and eliminate the root causes of environmental degradation. In the face of a threat of serious or irreversible harm, measures to prevent environmental degradation must not be postponed on the grounds of scientific uncertainty”(30).

Although the above-mentioned policies have touched upon severe and irreversible harm, it was Cass R. Sunstein who refined and theorized them. Sunstein’s “Catastrophic Harm Precautionary Principle” states that when catastrophic consequences are possible, special precautionary measures should be taken to deal with the worst-case scenario(31). This principle requires people to be aware of the underestimation and cognitive lag of catastrophic harm (possibly due to the “availability heuristic” and “scope neglect” theories mentioned when discussing survival risks), and thus calls for precaution in advance. Emphasizing precaution in advance is a common feature of any precautionary principle, which is in line with the forward-looking governance of emerging technology risks and is reasonable. Additionally, Sunstein, based on this principle, pointed out that risks can be divided into risks with known probabilities of possible consequences (narrowly defined risks) and risks with unknown probabilities of possible consequences (which he called uncertainties), and focused the governance concern of the precautionary principle on risks with unknown probabilities of possible consequences. This limited scope of concern will result in a limited scope of risk governance, thereby affecting the effectiveness of the precautionary principle in risk governance. Sunstein’s “Irreversible Harm Precautionary Principle” emphasizes that regulatory agencies can choose to postpone decisions when lacking information on the possibility and severity of risks to prevent irreversible harm(32). This principle proposes an important preventive measure, that is, to suspend the application process and wait for scientific research to increase the scientific information available for risk-benefit assessment. This measure can effectively prevent the occurrence of risks, but due to its singleness, it lacks flexibility in responding to risks.

4.1.2 Emphasize the cost-benefit trade-off

Emphasizing the cost-benefit trade-off is also a characteristic of the weak precautionary prin-

ciple. A typical example of this feature is the weak precautionary principle included in the environmental policies issued by the UK Department for Environment, Food and Rural Affairs. While focusing on the “significant risk of major harm”, this principle also stresses the importance of considering the cost of measures and tends to adopt a cost-benefit analysis approach.

To ensure that precautionary measures are commensurate with the likelihood of risks occurring, this principle distinguishes between two scenarios: “scientific knowledge is not yet conclusive” and “there are sufficient grounds to judge”, along with corresponding countermeasures. For the former scenario, the countermeasure is “as long as the cost-benefit analysis indicates it is reasonable, we can take precautionary measures to limit the spread of potentially hazardous materials or pollutants”; for the latter scenario, the countermeasure is “promptly take relatively low-cost actions to avoid potential greater harm in the future”(33).

The commonality of the two countermeasures lies in their use of the cost-benefit trade-off approach. The advantage of this approach is that it can minimize the occurrence of potential risks with low probability and/or low severity, causing widespread panic in society, as well as prevent the waste of human, material, and financial resources due to disproportionate precautionary measures compared to the actual risk level. The difference between the two countermeasures is that the latter is timely, while the former is lagging. The reason is that the logic of this countermeasure is to obtain sufficient scientific knowledge first, then make a trade-off based on that knowledge, and then take proportionate actions; if the scientific knowledge is insufficient, the actions cannot be implemented. For emerging technologies with uncertainties, specific cases with sufficient scientific knowledge can easily conduct cost-benefit trade-offs and take corresponding countermeasures; however, for specific cases with high scientific uncertainty, the practical effect of cost-benefit trade-offs is rather limited. Therefore, although emphasizing the trade-off is reasonable in general, in the governance of emerging technology risks, this method has limitations in its scope of application.

4.1.3 Emphasizing that the regulator bears the burden of proof

The third characteristic of the weak precautionary principle is that it places the burden of proof on the regulator rather than the regulated. Under this conception of the weak precautionary principle, the burden of proof lies with the regulatory body, which is responsible for envisioning potential harms and taking regulatory actions in advance; meanwhile, developers of new technologies do not need to prove that their technologies will not have negative impacts⁽³⁴⁾. The advantage of this feature is that it saves the energy of the developers and converters of new technologies, reduces their burden, builds a more relaxed relationship between regulators and the regulated, and is conducive to the accelerated development of emerging technologies in a more lenient regulatory environment.

However, it is unreasonable to place the burden of proof on regulators. One reason is that the number of technological research and development activities is huge, while the number of regulators is extremely limited. If the number of regulators is blindly expanded to cope with the numerous technological research and development activities and to identify specific matters with risks from the details of the research and development process, it will lead to excessively high governance costs and make regulatory activities unsustainable. The second reason is that the knowledge background of regulators may not match the rapidly evolving cutting-edge technological research and development activities. For some rapidly developing emerging technologies, only the researchers themselves have a better understanding of the potential risks involved. The third reason is that some regulated entities may conceal or disguise their technological activities, making it impossible for regulators to actually bear the burden of proof, as they may not be able to obtain genuine and effective information and data about the technological research and development activities, and thus cannot make evaluations and decisions.

Overall, the weak precautionary principle focuses on potential severe and/or irreversible risks and emphasizes the cost-benefit trade-off. These two

characteristics have a certain rationality. However, the weak precautionary principle with these two features can only deal with risks with known probabilities of occurrence, but cannot effectively respond to risks with scientific uncertainties promptly, thus having certain limitations in the governance of emerging technology risks. In addition, the requirement for regulators to bear the burden of proof under the weak precautionary principle cannot be achieved due to the diversity, complexity and uncertainty of knowledge in emerging technologies. However, the weak precautionary principle is still a type of precautionary principle, and thus has the forward-looking governance goal that is common to all precautionary principles. From this perspective, it has already surpassed the traditional lagging risk governance principles.

4.2 Effective governance under the strong precautionary principle

Compared with the weak precautionary principle, the strong precautionary principle has a stronger effect on risk governance. This enhanced governance effect is achieved through a more explicit division of responsible subjects and types of responsibility under this principle, as well as a more proportionate risk governance mechanism.

4.2.1 Clear responsibility subjects and types

The strong precautionary principle advocated by Noah M. Sachs, Frida Kuhlau, and others has made significant contributions to clarifying the responsible subjects and types.

Frida Kuhlau and others have proposed that both the regulated and the regulators should bear corresponding responsibilities. First, the regulated are the main bearers of the burden of proof; that is, the scientific community and individual participants have the responsibility to conduct information retrieval and prove, based on the retrieved information, that their research is not related to the assumed threats. Whether the responsibility should be borne by individual researchers or by the scientific community or the entire scientific field depends on the specific circumstances (for example, when expressing concerns about the intentions of a peer's research project, the indi-

vidual has the responsibility to bear the burden of proof; while in the risk review of dual-use technologies, the scientific community or the entire scientific field should bear the burden of proof). Second, the regulators have both the burden of proof and the responsibility for action. On the one hand, they need to provide information to prove that the risk is credible, and on the other hand, they need to take actions (i.e., precautionary measures) to respond effectively(35).

Here, there is a sequence in the burden of proof for researchers and regulators. Researchers should take the lead in shouldering the burden of proof, and the burden they bear is heavier. This is because the scientific uncertainty of emerging technologies means that regulators have access to information about emerging science much later than researchers on the front lines. In other words, regulators' understanding of emerging technologies depends on researchers' disclosure of information about emerging technologies. However, if researchers, as the regulated party, bear the burden of proof alone, it may affect their normal research progress. Therefore, the intervention and participation of regulators are needed.

The manifestation of the regulator's responsibility for action is to take precautionary measures to deal with risks. There are two bases for determining what precautionary measures to take. One is the "severity of the risk as a necessary prerequisite for taking precautionary measures"(36) proposed by Noah M. Sachs in his strong precautionary principle. That is to say, it is necessary to set up a "serious risk threshold" in advance, and based on the ratio of the risk level to the threshold, determine the implementation of precautionary measures, including comprehensive bans, restrictions, labeling and warning requirements, etc. Another approach is the "thresholds of seriousness and credibility" method proposed by Kuhlen et al. This method scientifically compares the severity and credibility of risks related to knowledge, technology, materials, etc. with the set thresholds, and takes commensurate precautionary measures based on the size of the ratio to the threshold. Among them, for risks that are less severe and less likely to occur compared to the threshold, the main responsibility of the regulator is to establish a risk awareness improvement mechanism and

encourage scientists to understand the outside world's concerns about technological risks; for risks that are more severe and more likely to occur compared to the threshold, the responsibility of the regulator is to call on and supervise a small number of scientists engaged in dangerous technology research to take greater cautionary responsibilities(37,38). It is not difficult to see that the latter is more conducive to regulators truly shouldering the responsibilities they should bear. The reason lies in that the latter places the credibility (i.e., the possibility of risk occurrence) on an equal footing with the severity, thus avoiding paying excessive and unnecessary governance costs due to "speculative concerns". This makes the extent of precautionary measures not only commensurate with the severity of the risk but also with the degree of uncertainty of the risk; thereby reasonably covering the entire range of emerging technology risks and "treating the right disease", preventing the situation where governance measures do not match the degree of risk.

In addition to the burden of proof and the responsibility for actions, Sachs also proposed that regulators should assume the role of "risk gatekeeper" and "decider". He assigned regulators the roles of "risk gatekeeper" and "decider". The responsibility of the "risk gatekeeper" is, on the one hand, to urge the supporters of actions or products to assume the burden of proof and conduct thorough research to prove the safety of the technology, thereby minimizing risks; on the other hand, it is to conduct "risks review" and "risk assessment" before actions with potential risks start or before products with potential risks enter the market - identifying which risks are serious and worthy of regulation. The responsibility of the "decider" is to determine whether the supporters of actions or products have fulfilled the burden of proof for verifying the safety of the actions or products(39).

Overall, the responsibility of researchers comes first, while that of regulators takes precedence. This division of responsibility and allocation of duties can not only give due attention to the scientific uncertainty characteristics of emerging technologies and ensure the safety of scientific research activities; but also minimize the burden on researchers and provide a relatively relaxed envi-

ronment for scientific research, thereby ensuring the healthy development of emerging technologies.

4.2.2 Proportional risk management

Proportional risk governance is also known as proportionate risk governance. Proportionality is an important feature of the principle of the strong precautionary principle. It can expand the scope and effectiveness of this principle. The proportionality of the strong precautionary principle has two meanings. One meaning is that the precautionary measures envisioned and taken should be commensurate with the expected level of protection, that is, the actor adjusts the measures according to the selected protection level(40); the other meaning is that the precautionary measures should be commensurate with the severity of the risk and the possibility of its occurrence(41).

Regarding the so-called “expected level of protection” in the first meaning, it should be noted that when dealing with emerging technologies, blindly pursuing zero risk is unrealistic. The first reason is that technological progress is always accompanied by risks, and there are no completely risk-free technological research and development activities; the second reason is that the extreme pursuit of approaching zero risk may require excessive human and material resources, and such a pursuit is not sustainable. Therefore, what “expected level of protection” that aims to achieve is risk control and appropriate protection. The situation of risk control and appropriate protection can fundamentally be regarded as not causing survival risks to humans, that is, not causing serious and irreversible impacts on human survival and development. When the universal goal faces specific emerging technology research and application, it can be set more specifically based on this universal goal and the relevant scientific information of the specific technology. For the so-called “designed and adopted precautionary measures” in the first meaning, it should be noted that complete prohibition may be one of the feasible methods to deal with potential risks, but it is not the only method. Other specific precautionary measures include taking restrictions, strengthening control, reducing exposure, adopting temporary limit values, providing advice to

high-risk groups, using safer research procedures or products for substitution, etc.

If the first layer of proportionality sets the macro framework for risk governance for the strong precautionary principle, then the second layer of proportionality gives the direct requirements for risk governance for this principle. The most in line with the direct requirements of proportionality is Per Sandin’s strong precautionary principle. Sandin’s precautionary principle emphasizes: if there is a threat and this threat is uncertain, then some compulsory action must be taken; the analysis of specific matters and their precautionary measures should be conducted in four dimensions: threat, uncertainty, command and action(42).

The “threat” in the dimension of threat mainly refers to a certain undesirable state that is caused by humans and may occur. The judgment of the size of the threat generally includes the severity (whether it is severe or not), reversibility (reversible or irreversible), and preventability (preventable or not preventable)(43). The “uncertainty” in the dimension of uncertainty refers to the state of our understanding or lack of understanding of possible world states. The judgment basis of the size of uncertainty is the level of our understanding of a certain action or product, that is, the reasonable degree of the risks disclosed by scientific evidence (the accuracy of the risks disclosed by scientific evidence). The lower the accuracy, the higher the uncertainty. The “command” in the dimension of instructions is also called regulations. These instructions can be classified into allowable, reasonable, recommended, and mandatory based on the degree of mandatoryness. The “action” in the dimension of action refers to what actions to take to respond to the threat, and the division of action caution and leniency is based on the scope of taking actions. The broader the scope of action, the more cautious it is, and the opposite indicates a more lenient situation. From this, it is easy to see that the requirement of “the risk governance means being commensurate with the severity and/or the possibility of risk occurrence” as proposed by Sandin is reflected in “the instructions and actions being commensurate with the threats and uncertainties”, thereby making the flexibility and operability of the precautionary principle in risk governance stronger.

Conclusion

Appropriate risk governance is a prerequisite and important guarantee for the stable development. How to handle the potential risks and safeguard the reasonable interests and development potential of both the current and future generations is of vital importance to the survival and prosperity of humanity.

Although the precautionary principle is generally forward-looking, not all precautionary principles are effective in the risk governance of emerging technologies. The limitations of the weak precautionary principle in terms of governance scope lead to its deficiency in effectiveness, thus making it not fully applicable. Critically inheriting the reasonable features of the weak precautionary principle and further developing the strong precautionary principle, which has a wide governance scope, flexible governance measures,

clear responsibilities, and strong operability, is more in line with the demands of contemporary risk governance characterized by rapid development and obvious uncertainty. In conclusion, strong precautionary principle is one of the important ethical principles in contemporary risk governance. Formulating corresponding norms, targeted guidelines and policies in combination with this ethical principle and specific real-world circumstances is the key next step to effectively control risks and ensure the stable development of society.

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THE CRIMINAL LAW REGULATORY LOGIC AND FUTURE PATHWAYS OF GENE EDITING TECHNOLOGY IN CHINA: SEVEN YEARS AFTER “GENE-EDITED BABIES”

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Abstract: The 2018 “gene-edited babies” incident marked a critical turning point in China’s criminal regulation of gene editing. Before the incident, China largely relied on administrative rules and ethical guidelines to govern gene-editing activities, without a systematic criminal legal framework or comprehensive regulatory mechanisms. In the aftermath, China intensified its efforts to establish stronger legal controls over gene-editing technology. This study examines the regulatory landscape seven years after the event, integrating empirical data on public awareness and perceptions of gene editing with a literature-based legal analysis of the current legislative framework and its deficiencies. Through this dual approach, the paper aims to deepen understanding of the evolution of China’s criminal regulation of gene editing and to provide policy insights for China and other developing countries seeking to strike a balance between scientific innovation and ethical as well as legal accountability.

Keywords: gene editing technology, criminal regulation, ethical issues, China

La lógica reguladora del Derecho Penal y las perspectivas futuras de la tecnología de edición genética en China: siete años después de los “bebés editados genéticamente”

Resumen: El incidente de los “bebés editados genéticamente” en 2018 marcó un punto de inflexión crucial en la regulación penal de la edición genética en China. Antes del incidente, China dependía en gran medida de normas administrativas y directrices éticas para regular las actividades de edición genética, sin un marco legal penal sistemático ni mecanismos regulatorios integrales. Tras el incidente, intensificó sus esfuerzos para establecer controles legales más estrictos sobre la tecnología de edición genética. Este estudio examina el panorama regulatorio siete años después del incidente, integrando datos empíricos sobre la concienciación pública y las percepciones de la edición genética con un análisis legal basado en la literatura del marco legislativo actual y sus deficiencias. A través de este doble enfoque, el artículo busca profundizar en la comprensión de la evolución de la regulación penal de la edición genética en China y proporcionar perspectivas políticas para China y otros países en desarrollo que buscan lograr un equilibrio entre la innovación científica y la responsabilidad ética y legal.

Palabras clave: tecnología de edición genética, regulación penal, cuestiones éticas, China

A lógica regulatória do direito penal e os caminhos futuros da tecnologia de edição gnetética na China: sete anos após os “bebês gneteticamente modificados”

Resumo: O incidente “bebês geneticamente modificados” marcou um ponto de virada na regulação penal da China sobre edição genética. Antes do incidente, a China dependia em grande parte de regras administrativas e diretrizes éticas para controlar atividades de edição genética, sem um arcabouço legal penal sistemático ou mecanismos regulatórios abrangentes. Após o ocorrido, a China intensificou seus esforços para estabelecer controles legais mais fortes sobre a tecnologia de edição genética. Esse estudo examina o cenário regulatório sete anos após o evento, integrando dados empíricos sobre conscientização e percepções do público em relação à edição genética com análise legal baseada na literatura do arcabouço legislativo atual e suas deficiências. Através dessa abordagem dual, esse artigo objetiva aprofundar a compreensão da evolução da regulação penal da China sobre edição genética e fornecer insights sobre políticas para a China e outros países em desenvolvimento buscando encontrar um equilíbrio entre inovação científica e a responsabilidade ética e legal.

Palavras chave: tecnologia de edição genética, regulação penal, questões éticas, China

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1. Introduction

The emergence of gene editing technology is widely regarded as a revolutionary breakthrough in the field of life sciences. It not only brings new hope for overcoming genetic diseases, improving treatment outcomes, and enhancing overall human health, but also opens up broad prospects for agricultural improvement and pharmaceutical development (1). With the advancement of AI, the integration of gene editing and intelligent algorithms is expected to significantly enhance research efficiency and accelerate profound transformations in medicine and life sciences (2). However, technological innovation often comes with risks. While benefiting humanity, it may also give rise to ethical dilemmas and safety concerns. For example, any error in germline gene editing could be transmitted across generations through heredity, leading to irreversible consequences, whereas human cloning and interspecies genetic chimeras could challenge the very foundations of human identity and ethical boundaries (3).

In China, the development of gene editing technology has also aroused widespread concern. The exposure of the “gene-edited babies” incident in 2018 not only shocked the academic community and the public at home and abroad but also pushed the conflict between the frontiers of life sciences and ethical boundaries to the center of public debate(4). In the aftermath, the Chinese government quickly took steps to strengthen criminal regulation, as it became increasingly clear that ethical review and administrative regulations alone were insufficient to provide effective constraints, and that criminal law should extend its reach to the domain of human gene editing(5). In response to public concerns, the *Amendment (XI) to the Criminal Law of the People's Republic of China* urgently introduced two offenses related to human genetic science—the crime of illegally carrying out human gene editing, cloning, and other reproductive medical activities, and the crime of illegally collecting or providing human genes, embryos, and other resources—thereby, to a certain extent, filling the legal gap in the criminal regulation of the abuse of human genetic technologies(6).

Time flies—seven years have passed since the

“Gene-Edited Babies” incident. This study seeks to address several key questions: What insights can empirical research on gene-editing technology, particularly in relation to the “Gene-Edited Babies” incident, provide? What is the current state of China’s legislative framework on gene editing, especially in terms of criminal regulation? And what deficiencies persist within the existing legal system governing gene-editing technology? The paper will systematically explore and analyze these issues to contribute to a deeper understanding of the legal and ethical governance of gene-editing in China.

2. Exploring the Reasons for the Criminalization of Gene Editing Technology

2.1 Gene Editing Technology Holds a Pivotal Strategic Position in China

Gene editing technology, as a revolutionary tool in the life sciences, has been assigned a highly strategic position in China. It is not only a core area of competition in cutting-edge science and technology but is also regarded as a key means to drive medical revolutions, ensure food security, and enhance the competitiveness of the bioeconomy (7). In 2016, the *National Innovation-Driven Development Strategy Outline* first proposed achieving breakthroughs in fields such as genomics and precision medicine(8). In 2020, *Biosecurity Law* further emphasized the safe governance and regulated development of biotechnology, including gene editing(9). In 2021, the Chinese central government, through top-level designs such as the *14th Five-Year Plan for Bioeconomy Development*, explicitly identified gene editing as a strategic scientific and technological direction and allocated substantial resources, aiming to achieve high-level technological self-reliance and secure a commanding position for future development(10). It can be seen that China’s strategic positioning is reflected in three main aspects:

- Treating gene editing as a critical technology for safeguarding national health and food security.
- Using it as an important driver of the bioeconomy and emerging industries.

- Leveraging it as a crucial asset for participating in global science and technology governance and Regulation formulation.

2.2 The application of gene editing technology has been advancing by leaps and bounds

China has taken a leading role in gene editing applications across multiple fields. In medicine, it launched the world's first human CRISPR clinical trial in 2016 and has since advanced both basic research and clinical trials, from studying cancer and genetic disorders to testing therapies for leukemia, lymphoma, B-thalassemia, and Duchenne muscular dystrophy (11). In agriculture, researchers use gene editing to improve rice, wheat, and corn for pest resistance, drought tolerance, and soil adaptability, while also enhancing livestock such as pigs resistant to African swine fever (12). In the industry, biomedical companies are rapidly investing in gene and cell therapies as well as molecular diagnostics, accelerating the commercialization of research and strengthening China's position in the global biomedical sector.

2.3 The Ethical Controversies Brought by Gene Editing Cannot Be Ignored

2.3.1 Hidden Genetic Discrimination

According to statistics, between 2000 and 2011, Chinese courts heard a total of 92 cases involving anti-discrimination claims, which were mainly concentrated in several categories. Among them, cases of discrimination against hepatitis B virus carriers were the most numerous, with 41 cases, accounting for 44.6% (13). This was followed by 9 cases of disability discrimination (9.8%), 8 cases of gender discrimination (8.7%), and 7 cases each of discrimination based on social origin and health status (7.6% each). In addition, there were 5 cases each of height discrimination and childbirth discrimination (5.4%), 4 cases of discrimination against HIV carriers (4.3%), 2 cases each of age discrimination and appearance-based discrimination (2.1%), as well as 1 case of regional discrimination and 1 case of employment discrimination caused by carrying pathogenic genes. Overall, discrimination against hepatitis B carriers dominated anti-discrimination cases, while genetic discrimination, though appearing

in only one case, already reflected the emergence of a new type of discrimination. Although there was just a single case of employment discrimination caused by carrying pathogenic genes among the 92 anti-discrimination cases, its significance goes far beyond the number itself. It not only reveals the potential of genetic information to become a new tool of discrimination but also reflects the lag in legal responses to emerging social risks brought about by technological development. As a concealed and forward-looking form of discrimination, genetic discrimination is gradually becoming a key area that future anti-discrimination law needs to address.

Gene-editing technology, while driving medical progress and disease prevention, also carries the potential risk of intensifying genetic discrimination (14). On the one hand, advances in gene editing have made genetic testing more sophisticated, making access to personal genetic information increasingly convenient. The misuse of such information could lead employers, insurance companies, or even educational institutions to treat individuals differently based on whether they carry certain genetic defects or have undergone genetic editing interventions, thereby infringing upon their rights to equality and privacy (15). On the other hand, the notion of "optimizing humanity" promoted by gene editing may fuel an excessive societal pursuit of "healthy" or "perfect" genes, which in turn could marginalize individuals who have not undergone genetic editing or who carry particular mutations. This not only reinforces inequalities in the distribution of social resources but may also, in subtle ways, create new forms of social stratification and discrimination.

2.3.2 Erosion of Social Equity and Fair Resource Distribution

Social equity represents an important value orientation of governance modernization in China, yet the development of gene editing technology may pose challenges to this goal. First, as a frontier technology with high costs and significant technical barriers, gene editing—if primarily controlled by a small group of elites or high-income classes—will lead to inequality in access and application (16). Such inequality is not only reflected in disparities in treatment opportunities but may also

generate intergenerational advantages through “genetic optimization,” thereby creating a “genetic divide.” Second, once this divide becomes entrenched, it may intensify existing social stratification and run counter to China’s current policy orientation of “common prosperity” (17). More seriously, if gene editing exerts implicit influences in areas such as education, employment, and social security, social stratification may acquire “technological” characteristics, resulting in entrenched and irreversible institutional inequality.

2.3.3 Risks to Ethnic Unity

The development of gene editing technology may provide individuals or groups with opportunities for “genetic optimization” based on hereditary traits (18). However, if access to this technology is distributed unequally, there is a risk of discrimination against specific groups or “non-optimized” individuals, thereby invisibly exacerbating inequalities both within and between ethnic groups. In China, ethnic unity and social harmony are regarded as fundamental pillars of national development. If gene editing is misused to promote evaluations of genetic “superiority” or to prioritize certain ethnic traits, it could not only undermine a sense of national identity but also weaken social cohesion, ultimately generating profound social and ethical challenges.

3. Empirical Analysis Regulatory Framework of Gene Editing Technology, and Exposed Issues

The year 2018 marked a pivotal point in the legal regulation of gene editing in China. In that year, He Jiankui announced the birth of the world’s first gene-edited babies, triggering widespread attention and ethical controversy both domestically and internationally, and exposing the existing legal gaps and regulatory deficiencies in China’s gene editing field (19). Therefore, this paragraph takes 2018 as a key node to examine the changes in relevant legislation before and after that year, and analyzes, based on survey data, the issues that still exist in the current application of gene editing technology in China.

3.1 Empirical Analysis on Public

A total of 1,200 questionnaires were distributed in this study, of which 1.08K(N=1080) were deemed valid, resulting in a valid response rate of 90%. The gender distribution was evenly balanced, with 540 males (50%) and 540 females (50%). Regarding educational attainment, Figure 1 presents that 216 participants (20%) had a high school education or below, 270 (25%) held an associate degree, 432 (40%) possessed a bachelor’s degree, and 162 (15%) had a master’s degree or above. This diverse sample composition ensures representativeness across gender and educational backgrounds, thereby providing a robust basis for analyzing variations in public awareness and attitudes toward gene-editing technology and related ethical and legal issues.

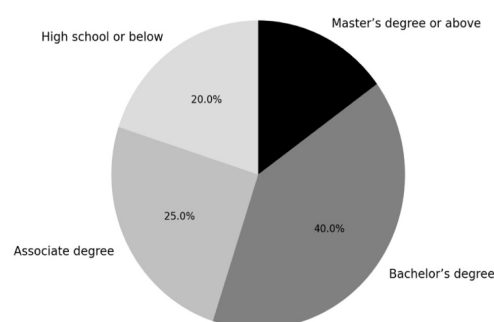


Figure 1: Educational Attainment of Respondents (N=1080)

To further verify this Correlation, data from Figure 2 demonstrate a clear upward trend in awareness with increasing education level. Specifically, only 30% of respondents with a high school education or below had heard of gene editing technology, compared with 40% among junior college graduates, 50% among those with a bachelor’s degree, and as high as 93% among master’s degree holders. Similarly, awareness of the He Jiankui gene-edited babies incident increased from 12% in the lowest education group to 44% in the highest. These results indicate that education level is a key determinant of public understanding of scientific and ethical issues: individuals with higher education not only possess greater exposure to scientific information but also

tend to adopt more rational and balanced attitudes toward emerging biotechnologies. Therefore, strengthening bioethics and science communication—particularly among groups with lower educational attainment—remains essential for fostering informed social dialogue and responsible public engagement.

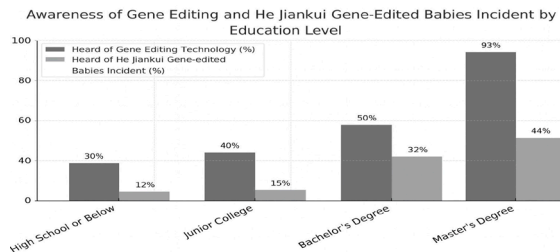


Figure 2: Empirical Research Data on Gene Editing Technology and the Gene-Edited Babies Incident

3.2 Legislative Changes Regarding Gene Editing Technology

Before 2018, China primarily relied on administrative regulations and ethical guidelines in the field of gene editing, such as the *Interim Measures for the Administration of Human Genetic Resources* (1998) and the *Ethical Guidelines for Human Embryonic Stem Cell Research* (2003), lacking clear criminal liability and a systematic regulatory framework². The He Jiankui gene-edited babies incident prompted the advancement of criminal legislation on gene editing in China, namely the *Criminal Law Amendment (XI)* (20). There are currently two offenses in Chinese criminal law related to human genetic technology: first, the crime of illegally collecting human genetic resources or smuggling human genetic material; and second, the crime of illegally implanting gene-edited or cloned embryos (21).

However, despite the criminal law clearly defining the scope of punishment and legal responsibility, numerous problems remain (22). First, the legal provisions do not fully keep pace with the rapid development of gene-editing technologies (23). New experiments such as CRISPR are constantly emerging, while the law's revision cycle is relatively

long, making certain behaviors difficult to clearly define (24). Second, the connection between criminal law and ethical review is insufficient. Overreliance on criminal sanctions may stifle scientific innovation, while ethical review alone is often inadequate to effectively prevent high-risk activities. Third, enforcement and judicial application face significant challenges. Gene editing involves highly specialized experiments and data, making evidence collection difficult, and the dispersed oversight by multiple departments can lead to regulatory gaps or duplicate penalties. Finally, there are obstacles to international coordination and cross-border governance. China's criminalization standards differ from countries that primarily rely on administrative and ethical oversight, which may increase legal risks for international scientific cooperation.

3.3 Exposed Issues

While the rapid development of gene-editing technology in China has promoted medical progress, it has also exposed numerous issues in legal and social governance. From the perspective of criminal regulation, current criminal law mainly addresses acts such as the illegal collection of human genetic resources and the unlawful implantation of gene-edited embryos. However, with the continuous emergence of new technologies like CRISPR, existing legal provisions have lagged, making certain behaviors difficult to clearly define (25). At the same time, ethical review exerts limited binding force in scientific research, and the connection between law and ethics is insufficient, with reliance on criminal penalties potentially inhibiting scientific innovation. Moreover, relevant regulations are dispersed across various laws and administrative documents, supervisory responsibilities overlap, coordination is inadequate, and alignment with international standards remains insufficient. At the public level, although some groups have a basic understanding of gene-editing technology, awareness of specific events remains low, particularly among individuals with lower educational attainment, reflecting uneven scientific literacy. Meanwhile, gene editing may lead to hidden discrimination and social fairness issues, and inadequate legal protection further heightens public concern over potential risks. In summary, the development of gene-editing

² Table 1: Key Legislative and Regulatory Frameworks for Gene Editing Technology in China.

Table 1: Key Legislative and Regulatory Frameworks for Gene Editing Technology in China

Date	laws and regulations	Ministry
1993	Administrative Measures for the Safety of Genetic Engineering	Science and Technology Committee
1998	Interim Measures for the Administration of Human Genetic Resources	Ministry of Science and Technology & Ministry of Health
2003	Ethical Guidelines for Research on Human Embryonic Stem Cells	Ministry of Science and Technology & Ministry of Health
2015	Administrative Measures for Clinical Research on Stem Cells (Trial)	National Health and Family Planning Commission & State Food and Drug Administration
2016	Measures for Ethical Review of Biomedical Research Involving Human Subjects	National Health and Family Planning Commission
2020	Safety Management Measures for Biotechnology Research and Development	Ministry of Science and Technology
2021	Civil Code of the People's Republic of China	National People's Congress
2021	Measures for Ethical Review of Life Sciences and Medical Research Involving Humans (Draft for Comment)	National Health Commission

technology exposes problems such as lagging legislation, weakened ethical constraints, fragmented regulation, and insufficient public awareness, necessitating responses through systematic legislation, strengthened ethics and public education, improved regulatory systems, and closer alignment with international standards.

4. Future Pathways for Improvement of Gene Editing Technology

4.1 Strengthening Public Participation

In the governance of gene editing technology, strengthening public participation is an essential approach to alleviating ethical controversies. At present, China's regulation of gene editing mainly relies on experts and administrative authorities, while the public often remains absent, resulting in insufficient social trust and information asymmetry. It is necessary to establish multi-level platforms for public communication, enabling diverse groups to express opinions in policymaking, ethical review of research, and risk assessment.

For example, public representatives could be introduced into the ethical review process of major scientific projects, or public awareness could be enhanced through science popularization and open hearings to ensure the right to know and participate. Public participation not only increases the transparency and legitimacy of decision-making but also helps achieve risk-sharing and balance of interests in a value-pluralistic society, thereby promoting the sustainable development of gene editing (26).

4.2 Improving the Legal and Regulatory Framework

Improving the legal and regulatory framework is a fundamental step to addressing ethical controversies. Although China has already amended the Criminal Law, introduced administrative regulations, and issued ethical guidelines to regulate illegal human gene editing activities, problems remain, including vague legal provisions, fragmented regulatory standards, and insufficient

enforcement (27). It is necessary to further refine legislation by clearly defining the boundaries of gene editing research and applications, particularly by setting strict prohibitions in areas involving human germ cells and embryos (28). At the same time, a coordinated regulatory mechanism should be established to ensure information sharing and joint enforcement among science, health, and judicial authorities, thereby enhancing regulatory effectiveness. By strengthening the legal framework and improving institutional enforcement, it is possible to safeguard scientific innovation while effectively preventing ethical and social risks.

4.3 Promoting Ethical Education and Scientific Self-Regulation

Promoting ethical education and scientific self-regulation is another important approach to addressing the ethical controversies surrounding gene editing. At present, some researchers, in their pursuit of academic breakthroughs and international competitiveness, tend to overlook a comprehensive assessment of ethical risks. To address this, bioethics education should be strengthened within the training system for researchers, making ethical competence an integral part of scientific capability. At the same time, research institutions should establish robust self-regulatory mechanisms, including internal rules, academic norms, and disciplinary measures, to create a system of clear responsibilities and effective accountability (29). The scientific community should also foster an academic culture that regards ethics as a fundamental bottom line, promoting both self-supervision and peer oversight to cultivate moral consciousness beyond institutional constraints. Only by emphasizing both ethical education and scientific self-regulation can scientific progress be advanced while avoiding the recurrence of ethical misconduct.

4.4 Promoting International Cooperation and Aligning with Global Standards

Promoting international cooperation and aligning with global standards is a necessary pathway for enhancing the governance of gene editing (30). Gene editing technology is highly transnational and shared, and relying solely on the regu-

lation of a single country is insufficient to comprehensively address potential ethical and safety risks. Therefore, China should actively participate in the development of international ethical guidelines and technical standards, fostering global consensus and coordinated mechanisms. At the same time, cross-border scientific collaborations require strengthened compliance review and risk assessment to prevent the emergence of “ethical loopholes,” where research circumvents ethical constraints due to regulatory differences. Aligning with international norms can not only enhance the legitimacy and credibility of domestic research but also promote innovation steadily in global scientific competition while upholding ethical standards and social responsibility.

5. Conclusion

Gene editing technologies, exemplified by CRISPR-Cas9, offer transformative scientific potential while simultaneously presenting profound legal and ethical challenges. The 2018 “gene-edited babies” incident in China exposed serious deficiencies in regulatory oversight, ethical governance, and public participation, highlighting the urgent need for a multidimensional governance framework. Such a framework should integrate robust legal regulation, transparent ethical review mechanisms, active public engagement, professional self-discipline within the scientific community, and strengthened international cooperation. Through this comprehensive approach, China can balance innovation with accountability, prevent unethical experimentation, and promote the responsible and sustainable development of gene editing technology. Future research should further explore public attitudes through empirical methods, assess comparative governance experiences across jurisdictions, and develop mechanisms to enhance compliance and ethical awareness, thereby contributing to the establishment of a more coherent, evidence-based, and globally harmonized governance system for emerging biotechnologies.

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EXPLORING THE ETHICAL BEHAVIOUR OF YOUTH ENGAGEMENT IN DIGITAL FINANCE: RISK PERCEPTIONS AND SECURITY VULNERABILITIES IN BIG DATA-DRIVEN SUPPLY CHAIN PLATFORMS

Tang Tao¹, Ma Yu Jie²

Abstract: The rapid proliferation of digital finance in emerging economies has prompted new inquiries into the ethical, strategic, and technological orientations of youth-led enterprises. This study investigates how fintech startups founded by young entrepreneurs in BRICS nations (Brazil, Russia, India, China, and South Africa) frame their organizational intent through mission and vision statements. Drawing upon a thematic analysis of 25 companies, the research examines the articulation of six critical constructs: ethical behavior, youth engagement, digital finance, risk perception, security vulnerabilities, and big data-driven supply chain platforms. The findings reveal a dominant emphasis on digital innovation and ethical positioning, with digital finance (34.7%) and ethical behavior (32.6%) emerging as the most frequently addressed themes. Conversely, risk-related narratives and cybersecurity discourse remain marginal, while youth engagement is conspicuously absent from most strategic texts, despite the demographic profile of the founders. Cross-national comparisons further underscore variation in thematic comprehensiveness, with Brazil and South Africa exhibiting the broadest strategic coverage. These results highlight both the potential and the narrative blind spots of youth-led digital finance enterprises in the Global South. The study advances theoretical discourse at the intersection of generational entrepreneurship, digital ethics, and platform governance, and offers actionable implications for regulators, investors, and founders aiming to foster resilient, inclusive, and ethically grounded fintech ecosystems.

Keywords: youth-led entrepreneurship, digital finance, ethical behavior, fintech in emerging markets, thematic analysis (BRICS)

Exploración del comportamiento ético de la participación de los jóvenes en las finanzas digitales: percepciones de riesgo y vulnerabilidades de seguridad en las plataformas de la cadena de suministro basadas en *Big Data*

Resumen: La rápida proliferación de las finanzas digitales en las economías emergentes ha impulsado nuevas indagaciones sobre las orientaciones éticas, estratégicas y tecnológicas de las empresas lideradas por jóvenes. Este estudio investiga cómo las startups fintech fundadas por jóvenes emprendedores en los países BRICS (Brasil, Rusia, India, China y Sudáfrica) definen su propósito organizacional a través de declaraciones de misión y visión. A partir de un análisis temático de 25 empresas, la investigación examina la articulación de seis constructos críticos: comportamiento ético, participación juvenil, finanzas digitales, percepción de riesgos, vulnerabilidades de seguridad y plataformas de cadenas de suministro basadas en big data. Los hallazgos revelan un énfasis dominante en la innovación digital y el posicionamiento ético, siendo las finanzas digitales (34,7%) y el comportamiento ético (32,6%) los temas más abordados. Por el contrario, las narrativas relacionadas con el riesgo y el discurso sobre ciberseguridad siguen siendo marginales, mientras que la participación de los jóvenes brilla por su ausencia en la mayoría de los textos estratégicos, a pesar del perfil demográfico de los fundadores. Las comparaciones transnacionales subrayan aún más la variación en la exhaustividad temática, siendo Brasil y Sudáfrica los que presentan la cobertura estratégica más amplia. Estos resultados resaltan tanto el potencial como los puntos ciegos narrativos de las empresas de finanzas digitales lideradas por jóvenes en el Sur Global. El estudio promueve el discurso teórico en la intersección del emprendimiento generacional, la ética digital y la gobernanza de plataformas, y ofrece implicaciones prácticas para reguladores, inversores y fundadores que buscan fomentar ecosistemas fintech resilientes, inclusivos y con fundamento ético.

Palabras clave: emprendimiento juvenil, finanzas digitales, comportamiento ético, fintech en mercados emergentes, análisis temático (BRICS)

Explorando o comportamento ético do envolvimento de jovens em finanças digitais: percepções de risco e vulnerabilidades de segurança em plataformas de cadeias de suprimento baseadas em megadados (*big data*)

Resumo: A rápida proliferação de finanças digitais em economia emergentes suscitou novas investigações sobre as orientações éticas, estratégicas e tecnológicas de empresas lideradas por jovens. Esse estudo investiga como startups de fintech criadas jovens empreendedores em nações do BRICS (Brasil, Rússia, Índia, China e África do Sul) definem sua intenção organizacional por

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meio de declarações de sua missão e visão. Com base em uma análise temática de 25 empresas, a pesquisa examina a articulação de seis constructos críticos: comportamento ético, envolvimento de jovens, finança digital, percepção de risco, vulnerabilidades de segurança e plataforma de cadeias de suprimento baseadas em megadados (big data). Os achados revelam uma ênfase dominante em inovação digital e posicionamento ético com finança digital (34,7%) e comportamento ético (32,6%) emergindo como temas mais frequentemente contemplados. Em contrapartida, narrativas relacionadas a risco e discurso sobre segurança cibernética permanecem marginais, enquanto envolvimento de jovens está manifestamente ausente da maioria dos textos estratégicos, a despeito do perfil demográfico dos fundadores. Comparações transnacionais reforçam ainda mais a variação em abrangência temática, com o Brasil e a África do Sul exibindo a cobertura estratégica mais abrangente. Esses resultados ressaltam tanto o potencial quanto os pontos cegos da narrativa de empreendimentos de finança digital liderados por jovens no Sul Global. O estudo contribui para o discurso teórico na intersecção do empreendedorismo intergeracional, ética digital e governança de plataforma, oferecendo soluções práticas para reguladores, investidores e fundadores que buscam fomentar ecossistemas de fintech resilientes, inclusivos e eticamente baseados.

Palavras chave: empreendedorismo liderado por jovens, finança digital, comportamento ético, fintech em mercados emergentes, análise temática (BRICS)

Introduction

The rapid expansion of digital finance in emerging economies has significantly transformed the financial inclusion framework, particularly within the BRICS nations—Brazil, Russia, India, China, and South Africa. These countries, characterized by vibrant youth demographics and swiftly digitizing economies, are progressively depending on novel financial technology to address conventional disparities in economic engagement. Youth-led digital finance firms have arisen as drivers and indicators of extensive socio-technological transformations. Nonetheless, their involvement is fraught with ethical, operational, and structural issues, especially at the intersection of digital finance, big data, and supply chain infrastructures(1).

The digital banking landscape necessitates examining the interplay between ethical conduct, adolescent involvement, and risk perception. Young entrepreneurs are responding to technological advancements and actively influencing the ethos and architecture of financial services in their nations. Their participation in founding organizations that adopt ethical frameworks and manage the intricacies of risk, data security, and transparency is particularly crucial in evolving regulatory landscapes where these considerations remain underdeveloped. As digital ecosystems proliferate, concerns regarding security risks and data governance are increasingly integrated into the strategy frameworks of these youth-led firms(2,3).

This study adopts an innovative methodology by analyzing the vision and mission statements of digital finance enterprises established by young entrepreneurs in BRICS nations. This study employs a comparative thematic analysis of key strategic papers to reveal how young founders express ethical ideals, tackle risk and security issues, and conceptualize youth involvement in data-driven financial contexts. These vision and mission statements function as declarations of organizational intent and as culturally and contextually integrated texts that disclose underlying objectives, assumptions, and socio-technological commitments(4,5).

This inquiry emphasizes big data-driven supply chain platforms, recognizing the growing convergence of financial services and digital logistics systems across BRICS economies. This interconnection is essential for comprehending how emerging digital finance firms recognize and address operational weaknesses and ethical obligations in high-volume, data-intensive contexts. The study examines whether these firms regard adolescent participation as a strategic and ethical necessity in digital transformation rather than a demographic issue(6,7).

This research analyses 25 companies—five from each BRICS nation—to create a cross-national thematic map of values, narratives, and strategic priorities inherent in youth-led fintech entrepreneurship. The objective is to discern convergent and divergent patterns in integrating ethical behavior, digital finance inclusion, risk awareness, and data security consciousness within the foundational visions of these companies. This investigation enhances comprehension of youth agencies in digital economies and facilitates more refined policymaking and governance frameworks that address the ethical aspects of fintech development in emerging regions(8,9).

Literature review

Overview of Digital Finance in BRICS Economies

The digital financial scene in BRICS nations has developed due to technical progress, legislative liberalization, and socio-economic demands. Each BRICS nation demonstrates unique paths in fintech advancement—China and India excel in payment infrastructure and financial inclusion, Brazil pioneers open banking frameworks, Russia promotes cryptocurrency adoption despite regulatory challenges, and South Africa integrates formal and informal finance via mobile technologies(10). Nonetheless, despite common goals of financial democratization, these economies encounter inherent inequalities in digital infrastructure, regulatory sophistication, and overall digital literacy among the people. The variability in digital finance adoption highlights the necessity to contextualize technical dissemination within national institutional frameworks and state-market interactions(11).

While digital finance is frequently lauded for enhancing accessibility and efficiency, it simultaneously exacerbates pre-existing power and data governance disparities. The regulation of digital financial services is inconsistent among BRICS nations, exhibiting disparities in enforcing consumer protection, data privacy, and cybersecurity standards. Furthermore, the swift expansion of fintech has, in certain cases, surpassed the capabilities of financial regulators, leading to disjointed oversight and regulatory gaps. These characteristics undermine the presumption that digital money within BRICS is intrinsically inclusive or stable. A comprehensive examination is necessary—one that combines macro-level development frameworks with micro-level user experiences and socio-cultural adaptations of digital financial instruments(12,13).

Youth Entrepreneurship in Fintech Ecosystems

Youth entrepreneurship in fintech embodies a dynamic of disruption and democratization in emerging economies. Within BRICS, emerging entrepreneurs are utilizing mobile-first frameworks and blockchain technology to combat financial disadvantages while simultaneously transforming the cultural narrative of entrepreneurship from an elite legacy to one grounded in digital-native adaptability. Government initiatives, including start-up incubators, fintech sandboxes, and digital innovation grants, have fostered youth-led enterprises; however, the degree of youth integration into fintech ecosystems is contingent upon educational access, capital availability, and regional innovation hubs. Youth entrepreneurship often thrives despite structural limitations, propelled by necessity as much as opportunity(14-16).

However, the joyful narrative around youth-led fintech frequently neglects structural obstacles and ethical oversights. Inadequate governance experience, immature risk management protocols, and a lack of awareness about socio-cultural ethics may render youth-led enterprises susceptible to mission drift, technology overextension, and the misuse of user data. Furthermore, the fetishization of “disruption” may diminish the significance of the long-term sustainability and social responsibility of these firms. Consequently,

the analysis of youth entrepreneurship in fintech should extend beyond innovation measurements to encompass ethical frameworks, intergenerational power dynamics, and the socio-political integration of youth into digital financial ecosystems(17).

Ethical Behavior in Digital Financial Services

Ethical considerations in digital financial services encompass justice, openness, responsibility, and trust. Numerous digital finance transactions’ intangible and automated characteristics have challenged conventional understandings of ethical behavior in service provision. In BRICS nations, where initiatives for financial inclusion frequently engage marginalized and digitally disadvantaged groups, the consequences of ethical failures are especially significant(18). Concerns like algorithmic bias, unethical micro-lending, opaque fee structures, and predatory surveillance tactics undermine the ethical integrity of new financial platforms. Moreover, unethical practices may continue to thrive, masquerading as innovation and convenience in settings devoid of stringent consumer data protection legislation or financial literacy(19,20).

Ethics in digital finance is fundamentally a strategic and cultural attitude integrated into the organizational architecture rather than solely a compliance issue. Numerous fintech companies, especially startups, lack established ethical frameworks or formal accountability systems, instead depending on swift experimentation and market-driven adjustments. This may result in a disconnect between technological proficiency and ethical accountability(21). As digital financial ecosystems become more integrated with supply chains, health systems, and identity infrastructures, ethical violations pose a risk of systemic consequences. Consequently, examining ethical conduct in digital finance must scrutinize organizational aims and infrastructural ramifications, especially in youth-led enterprises where growth demands may eclipse ethical foresight(22).

Youth Engagement, Risk, and Systemic Challenges in Digital Finance and Supply Chain Integration

Engagement and agency of youth in technological innovation are crucial in influencing the digital finance sector within BRICS nations, as young entrepreneurs serve as both users and creators of financial innovations. Their involvement signifies a generational transition towards nimble, mobile-centric solutions that rectify deficiencies in financial inclusion. This engagement transpires within intricate risk landscapes where perceptions of digital finance risks—such as fraud, volatility, and privacy breaches—are frequently influenced by inadequate financial literacy and emerging regulatory control(23). These risk perceptions affect adoption behaviors and design decisions in youth-led platforms, leading to underestimating systemic vulnerabilities or overcompensation through excessively cautious architectures. Concurrently, the dependence on big data engenders significant security concerns, particularly in startups where cybersecurity resources may be inadequate and ethical foresight is weak. Integrating financial services with digital supply chain platforms heightens concerns around data quality, algorithmic fairness, and platform governance due to the convergence of logistical and transactional data. These dynamics underscore the importance of critically examining how youth-led digital finance initiatives in BRICS navigate innovation, risk, and responsibility in technologically complex and institutionally diverse ecosystems(24).

Vision and Mission Statements and Thematic Analysis in Strategic Communication

Vision and mission statements embody an organization's fundamental identity, long-term goals, and ethical principles. Within youth-led digital finance enterprises, particularly in BRICS countries, these statements serve as marketing instruments and narrative structures that elucidate how young founders perceive their influence in constructing socio-technical futures. Vision statements generally express aspirational objectives and future-focused principles, whereas mission statements highlight present operational strategies and obligations to stakeholders(25). Together, they embody the founders' ingrained views regarding ethics, innovation, youth involvement, risk accountability, and their expected impact on financial ecosystems. Examining these documents offers an essential understanding of the discursive

formation of youth entrepreneurship and the articulation of ethical principles and digital priorities to internal and external stakeholders(26).

The thematic analysis provides a rigorous qualitative approach for methodically deriving meaning from strategic texts in strategic communication research. This method allows researchers to discern, examine, and elucidate patterns of significance—termed themes—within textual data. Thematic analysis reveals overt commitments and underlying discourses that influence the direction of an organization's vision and mission statements. It is especially beneficial in comparative cross-national research since it facilitates the discovery of culturally and contextually specific narratives while simultaneously uncovering broader similarities across cases. This study utilizes thematic analysis to identify recurring constructs such as ethical behavior, youth empowerment, digital inclusivity, risk awareness, and security consciousness—elements that delineate organizational priorities and reflect the socio-political and technological environments of BRICS nations(27,28).

Cross-National Perspectives on Fintech Ethics and Governance

The ethics and governance of fintech vary significantly among countries, shaped by varying regulatory capabilities, cultural standards, and degrees of technology advancement. The variation across BRICS countries is particularly evident, as each government implements unique policy frameworks, compliance standards, and institutional responses to the swift expansion of digital banking. China's paradigm prioritizes state-driven governance and data sovereignty, whereas Brazil embraces open banking initiatives bolstered by progressive regulatory frameworks(29). Geopolitical limitations and fragmented cryptocurrency initiatives hinder Russia's strategy, while India advances financial inclusion via Aadhaar-integrated digital identification frameworks. Although smaller, South Africa's fintech sector is characterized by hybrid governance structures integrating informal financial practices with formal digital innovations. Diverse methodologies influence the comprehension and implementation of ethical issues across international boundaries, such as data privacy, algorithmic responsibility, and

user protection. A cross-national view provides a crucial framework for comprehending that ethics in fintech are not universal but contested within distinct political, economic, and cultural contexts(30,31).

Nonetheless, these national disparities result in a fragmented global framework where fintech governance is applied inconsistently, especially concerning youth participation, systemic risk, and technology accountability. Fintech businesses founded by youth frequently function in ambiguous legal environments where legislative progress fails to keep pace with technological innovation. Some jurisdictions provide regulatory sandboxes and incentives for youth, while others lack institutional backing for ethical entrepreneurship, heightening the danger of governance failures. A comparative cross-national approach elucidates best practices and regulatory advances while revealing normative tensions between innovation and control, inclusiveness and surveillance, profit and accountability. This approach is crucial for comprehending how BRICS nations may jointly establish ethical norms adaptable to local contexts while maintaining sufficient rigor to guarantee systemic integrity in digital finance(32,33).

Gaps in Literature: Interlinking Ethics, Youth, and Supply Chain Finance

Notwithstanding the expanding corpus of research on fintech innovation, digital inclusion, and ethical governance, a significant gap persists in the literature regarding the nexus of youth entrepreneurship, ethical conduct, and digital supply chain finance—especially in emerging markets such as the BRICS nations. Current research frequently addresses these domains in isolation: youth engagement is typically analyzed through startup ecosystems or digital adoption metrics; ethical behavior is considered in abstract or compliance-focused contexts; and supply chain finance is predominantly investigated from operational or institutional viewpoints. This compartmentalization neglects the interrelated manner in which young fintech founders are shaping—and being shaped by—the developing ethics of financial-technological integration in supply chain environments. The scant research addressing these intersections predominantly concentrates on

Global North economies or major multinational firms, neglecting youth-driven innovation in the Global South(34). This study focuses on young agencies as a key driver of ethical innovation in digital supply chain finance. This research examines how young entrepreneurs in BRICS nations express their ethical convictions in strategic texts, particularly vision and mission statements, thereby uncovering the evolving values, goals, and risk sensitivities influencing the future generation of fintech infrastructures(35,36).

Methodology

Research Methodology

This study employs a qualitative, exploratory, and cross-national comparative framework to examine how youth-led digital finance enterprises in BRICS nations articulate ethical conduct, risk awareness, and strategic orientations in their vision and mission statements(37,38). The research operates within an interpretive framework, focusing on deriving meaning from strategic textual narratives instead of quantifying performance metrics. The selection of vision and mission statements as the unit of analysis is based on their role as authoritative documents that articulate organizational principles, stakeholder commitments, and strategic identity(39-41).

Sampling Methodology

A purposive sample method was utilized to discover youth-founded digital finance enterprises in the five BRICS nations—Brazil, Russia, India, China, and South Africa. Five companies were chosen from each country (total n=25) according to the following criteria: (1) established or co-established by an individual aged 35 or younger at the time of the company's inception; (2) currently functioning within the digital finance sector, encompassing, but not limited to, digital payments, lending platforms, cryptocurrency finance, or supply chain financing; (3) possessing publicly available and official vision and mission statements disseminated through websites, investor reports, or policy documents. This sampling guaranteed geographic, cultural, and technological diversity within the digital financial ecosystem while preserving theme coherence(42).

Data Acquisition

Data were gathered from official corporate websites, annual reports, white papers, and authenticated third-party fintech directories from May to July 2025. Each company’s vision and purpose statements were obtained in their original format. Certified translations were procured for statements unavailable in English to verify semantic accuracy. Secondary data, including founder profiles, launch dates, and platform types, were collected to enhance contextual understanding but were not analyzed thematically in the primary analysis.

Analytical Procedure

The research utilized thematic analysis as its primary analytical approach, adhering to Braun and Clarke’s six-step framework: familiarisation, initial coding, theme development, theme review, theme definition, and report generation. Vision and mission statements were input into qualitative analysis software (e.g., NVivo) to enable inductive and deductive coding. A hybrid coding approach was employed: inductive codes arose organically from the data, whereas deductive codes were guided by the study’s theoretical framework—specifically, the keywords contained in the research title: ethical behavior, youth engagement, digital finance, risk perceptions, security vulnerabilities, and big data-driven supply chain platforms. This method facilitated the identification of emergent themes and the validation of concepts(42).

Cross-National Comparative Framework

The thematic outcomes were compared within and within BRICS nations to guarantee analytical rigor across national examples. Thematic patterns were analyzed considering institutional, regulatory, and socio-economic contexts, facilitating the interpretation of common and differing strategic aims. Patterns were analyzed for thematic density, recurrence, and conceptual overlaps to discern macro-level trends and micro-level variations. A comparison matrix was created to visually represent the significance of the theme by country and evaluate how national settings influence ethical, technological, and risk-related discourses in

youth-led fintech ventures(43).

Reliability and Authenticity

To guarantee credibility, transferability, and confirmability, the study utilized methodological triangulation by validating vision and mission statements with publically accessible interviews and investor briefings, when applicable. Peer debriefing sessions and inter-coder agreement assessments confirmed the consistency of coding. Reflexivity was upheld during the analytical process to oversee researcher bias, especially in understanding ethical intent from business discourse(38).

Data Analysis

Brazilian Companies

Table 1 Brazilian Youth-Led Digital Companies

S No.	Theme	Frequency	Percentage
1	Ethical Behavior	5	100%
2	Youth Engagement	0	0%
3	Digital Finance	5	100%
4	Risk Perception	1	20%
5	Security Vulnerabilities	1	20%
6	Big Data-Driven Supply Chain Platforms	1	20%

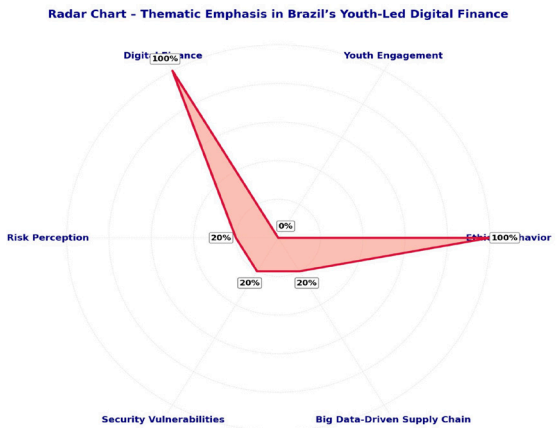


Figure 1 Brazilian Youth-Led Digital Companies.

Table 1 and Figure 1 show the thematic analysis of five youth-founded Brazilian digital finance companies reveals a strong and consistent empha-

sis on ethical behavior and digital finance, with both themes appearing in 100% of the vision and mission statements. These companies frequently employ terms such as “empower,” “inclusive,” “transparent,” and “accessible,” signaling a shared strategic commitment to ethical values in the delivery of financial services. This linguistic framing positions them not just as technological ventures but as ethically responsible institutions aiming to democratize financial access. Likewise, the universal presence of digital finance-related terminology reflects the core nature of their business models—ranging from neobanking to mobile wallets and automation—highlighting the extent to which digital transformation is embedded in their operational and value narratives.

In contrast, other thematic areas receive significantly less attention. Notably, youth engagement is absent from all five companies’ strategic statements, even though each organization was founded by individuals under the age of 30.6. This absence suggests a disconnect between the age of the founders and the demographic framing of their platforms. Rather than emphasizing generational leadership or youth empowerment in finance, the statements adopt a broader, more universal consumer focus. Similarly, risk perception and security vulnerabilities each appear in only one company’s statements, indicating a low frequency of concern—at least in rhetorical terms—for cybersecurity, data protection, or user risk awareness. This underrepresentation is particularly surprising given the financial sector’s inherent exposure to digital threats and user trust concerns.

A minimal presence was also found for references to big data-driven supply chain platforms. Only one company, Asaas, touched on concepts related to process automation and efficiency—indirectly referencing backend technological infrastructure. This suggests that while data and automation may be core to operations, they are not being prominently communicated as strategic themes. Demographically, the founders of these firms average approximately 30.6 years of age, solidly within the youth entrepreneurship bracket. However, the fact that youth engagement is not explicitly highlighted implies a deliberate choice to separate personal identity from public branding.

Russian Companies

Table 2 Russian Youth-Led Digital Companies

S No.	Theme	Frequency	Percentage
1	Ethical Behavior	3	60
2	Youth Engagement	0	0
3	Digital Finance	1	20
4	Risk Perception	1	20
5	Security Vulnerabilities	0	0
6	Big Data-Driven Supply Chain Platforms	3	60

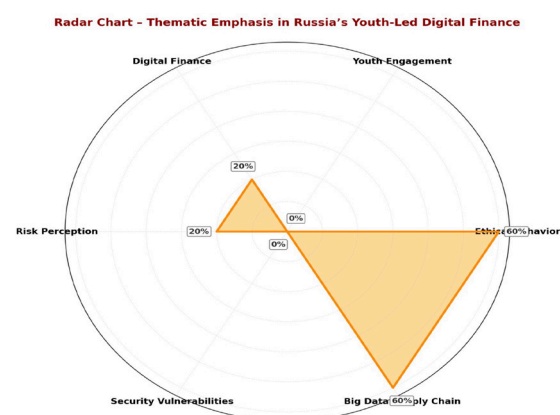


Figure 2 Russian Youth-Led Digital Companies

Table 2 and Figure 2 show the thematic analysis of vision and mission statements from five youth-founded Russian digital finance companies present a nuanced picture of how these firms frame their strategic and ethical priorities. Ethical behavior emerges as a prominent theme, present in 60% of the companies. This suggests that a majority of the selected companies position themselves as purpose-driven or socially responsive, using terms like “accessible,” “democratize,” or “transform” to communicate a value-oriented mission. However, unlike Brazilian companies—where ethical language was universal—this figure indicates a less consistent emphasis on ethical positioning in the Russian digital finance narrative.

Interestingly, the theme of **youth engagement** is again absent, despite the relatively young average founder age of **33.2 years**. This may indicate that Russian founders, much like their Brazilian counterparts, do not consider age or generational identity to be a strategic differentiator in their

public communications. Their messaging remains focused on product functionality and technological disruption rather than demographic or generational branding.

The **digital finance** theme, which was expected to dominate given the nature of the sector, appears in only 20% of the companies. This is surprisingly low and suggests that while these firms operate within or adjacent to fintech, many describe themselves more broadly as platforms, tech innovators, or infrastructure providers. For example, companies like Samokat and Planeta.ru lean more toward logistics or crowdfunding ecosystems, and their strategic language reflects that broader scope.

Risk perception appears in just one company, accounting for 20% of the sample, highlighting a limited engagement with themes related to safety, protection, or risk management. In a digital context where trust and cybersecurity are foundational, this absence raises questions about how risk-related assurances are communicated—if at all—within startup narratives. Compounding this is the complete absence (0%) of language associated with **security vulnerabilities**, such as data protection or privacy, which is particularly notable for companies involved in investment, payments, or user data-driven services.

A standout feature in the Russian data is the unexpectedly high occurrence of the theme **Big Data-Driven Supply Chain Platforms**, found in 60% of the companies. This suggests that several Russian startups view themselves as technology infrastructure providers or enablers of process and platform-based efficiencies. The frequent use of terms like “platform,” “efficiency,” and “process” underscores their commitment to backend innovation and system-wide integration, even when it’s not explicitly branded as “big data” in the traditional sense. This differentiates the Russian fintech narrative from Brazil’s, where this theme was marginal.

Indian Companies

Table 3 Indian Youth-Led Digital Companies

S No.	Theme	Frequency	Percentage
1	Ethical Behavior	4	80
2	Youth Engagement	1	20
3	Digital Finance	4	80
4	Risk Perception	0	0
5	Security Vulnerabilities	0	0
6	Big Data-Driven Supply Chain Platforms	0	0

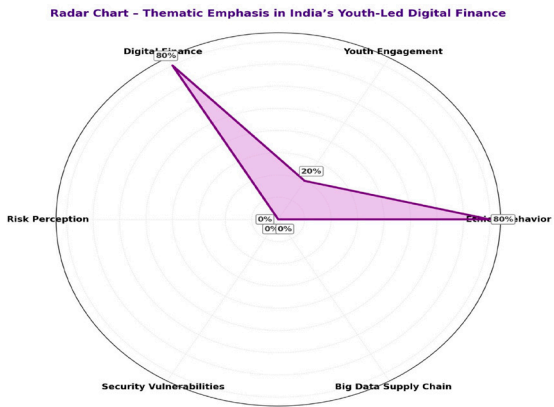


Figure 3 Indian Youth-Led Digital Companies

Table 3 and Figure 3 highlight that Indian youth-led digital finance firms strongly emphasize *ethical behavior* and *digital finance*, each present in 80% of cases. These companies frequently reference inclusivity, transparency, and access, reflecting a clear commitment to socially responsible innovation. Their operational language centers on digital tools such as credit platforms and online financial services, showcasing a digitally native business orientation. However, *youth engagement* appears in only one firm (20%), indicating limited alignment between the founders’ generational identity and their public messaging. This suggests a missed opportunity to brand themselves as generational change-makers, despite often targeting younger users. More critically, none of the companies reference *risk perception*, *security vulnerabilities*, or *big data supply chain platforms*. This omission may signal a strategic blind spot, particularly concerning user trust and platform security—vital in a context like India, where data privacy and fintech regulation are high-stakes

concerns. With an average founder age of 30.6 years, Indian fintechs meet the youth-led criterion but fall short in incorporating youth identity, platform risks, or data ethics into their strategic narratives. While their ethical and digital foundations are strong, stronger messaging on security, risk, and generational engagement could enhance differentiation and trust.

China

Table 4 Chinese Youth-Led Digital Companies

S No.	Theme	Frequency	Percentage
1	Ethical Behavior	1	20
2	Youth Engagement	0	0
3	Digital Finance	2	40
4	Risk Perception	0	0
5	Security Vulnerabilities	0	0
6	Big Data-Driven Supply Chain Platforms	2	40

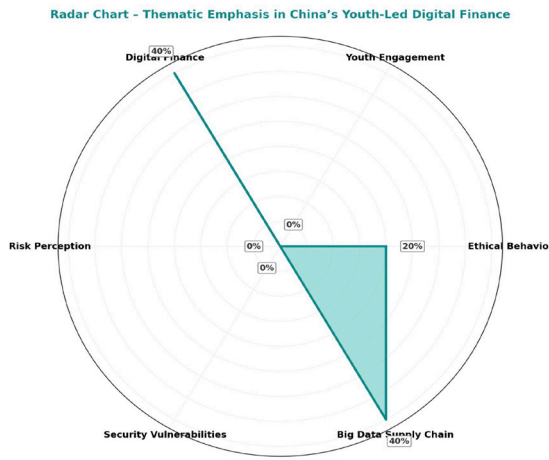


Figure 4 Chinese Youth-Led Digital Companies

South African youth-led digital finance firms in Table 4 and Figure 4 show strong emphasis on *digital finance* (80%) and moderate attention to *risk* and *security* (40%), reflecting a growing focus on platform reliability and inclusion. *Ethical behavior* is present but limited (40%), while *youth engagement* is entirely absent despite an average founder age of 31.6. This suggests a preference for institutional credibility over generational identity, pointing to an opportunity for more youth-reflective communication.

South Africa

Table 5 South African Youth-Led Digital Companies

S No.	Theme	Frequency	Percentage
1	Ethical Behavior	2	40
2	Youth Engagement	0	0
3	Digital Finance	4	80
4	Risk Perception	2	40
5	Security Vulnerabilities	2	40
6	Big Data-Driven Supply Chain Platforms	1	20

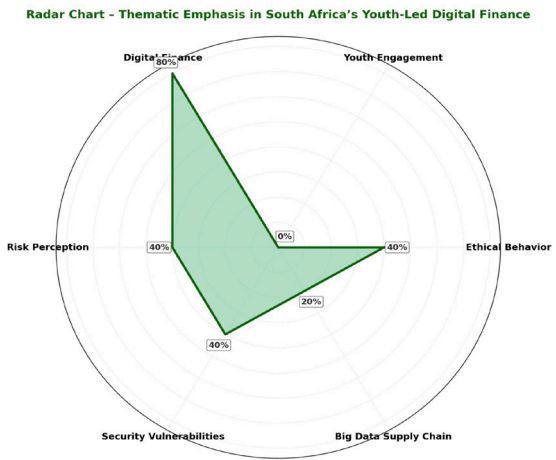


Figure 5 South African Youth-Led Digital Companies

Table 5 and Figure 5 highlight that South African youth-led digital finance firms strongly prioritize *digital finance* (80%), with firms like Yoco and TymeBank emphasizing innovation, inclusion, and payment accessibility. *Ethical behavior* appears in 40% of companies, reflecting partial commitment to values like affordability and empowerment. Notably, South Africa leads BRICS peers in *risk perception* and *security* discourse (40%), with firms explicitly referencing secure data practices and system reliability—suggesting a more mature fintech narrative. Despite founders averaging 31.6 years, *youth engagement* is entirely absent from public messaging, mirroring patterns across other BRICS nations. This signals a strategic preference for institutional credibility over generational identity, leaving a potential gap in youth-centered branding and inclusion.

Table 6 Country vs Thematic words highlighted BRICS

Theme	Brazil	Russia	India	China	South Africa	Total	Total (%)
Big Data-Driven Supply Chain Platforms	1	3	0	2	1	7	15.2
Digital Finance	5	1	4	2	4	16	34.7
Ethical Behavior	5	3	4	1	2	15	32.6
Risk Perception	1	1	0	0	2	4	8.6
Security Vulnerabilities	1	0	0	0	2	3	6.5
Youth Engagement	0	0	1	0	0	1	2.1
Total	13	8	9	5	11	46	
Total (%)	28.3	17.4	19.6	10.9	23.9		100

Overall, country vs. thematic words highlighted BRICS

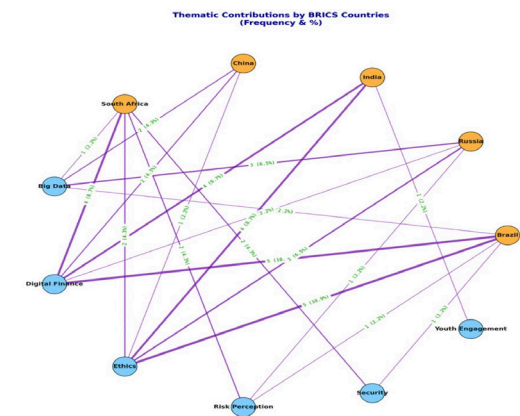


Figure 6 Country vs Thematic words highlighted BRICS

Table 6 and Figure 6 present the thematic focus of BRICS youth-led digital finance companies across six variables: *Ethical Behavior*, *Youth Engagement*, *Digital Finance*, *Risk Perception*, *Security Vulnerabilities*, and *Big Data-Driven Supply Chain Platforms*. *Digital Finance* (34.7%) and *Ethical Behavior* (32.6%) were the most emphasized themes, indicating a shared strategic orientation toward technological innovation and social inclusion. This aligns with the study’s focus on ethical youth engagement in digital ecosystems. *Big Data Supply Chain* themes (15.2%) appeared mostly in Russia and China, highlighting a regional focus on platform infrastructure and backend optimization. In contrast, Brazil, India, and South Africa showed minimal emphasis in this area. *Risk Perception* (8.6%) and *Security Vulnerabilities* (6.5%) were underrepresented overall, with

South Africa being the only country addressing both to a meaningful degree. This raises concerns about narrative gaps in trust-building and digital resilience. *Youth Engagement*—central to the study—was nearly absent, appearing in only one Indian company (4%). This reflects a disconnect between founder identity and brand communication, suggesting a missed opportunity to highlight generational leadership. Cross-nationally, Brazil and South Africa exhibited the most comprehensive thematic profiles, each covering five out of six themes. China and Russia focused narrowly on digital and infrastructure-related topics, while India showed strength in ethical and digital framing but lacked security-related themes.

Discussions

This study examined how youth-led digital finance companies in BRICS countries strategically frame six key themes in their mission and vision statements: *Ethical Behavior*, *Youth Engagement*, *Digital Finance*, *Risk Perception*, *Security Vulnerabilities*, and *Big Data-Driven Supply Chain Platforms*. Analyzing 25 firms revealed both shared priorities and distinct regional narratives. Thematically, *Digital Finance* (34.7%) and *Ethical Behavior* (32.6%) dominated, highlighting a focus on inclusion, accessibility, and responsible innovation. Brazil and India emphasized ethical messaging, while Russia and China leaned toward infrastructural and data-driven positioning. *Big Data* themes (15.2%) were largely championed by Russia and China, whereas *Risk* (8.6%) and *Security* (6.5%) were widely under-addressed, with only South Africa showing moderate attention. A critical gap was *Youth Engagement*, mentioned by just one company, despite all founders

being under 35. This points to a broader trend: young fintech entrepreneurs favor institutional and technical legitimacy over generational identity. Brazil and South Africa exhibited the most balanced thematic coverage (83.3%), while China and India addressed only half the key themes. Visual mappings reinforced these asymmetries, emphasizing the role of national context in shaping strategic discourse.

Conclusion

This study analyzed how youth-led digital finance companies across BRICS nations frame their strategic focus through six core themes. Thematic analysis of 25 firms revealed strong emphasis on *digital finance* and *ethical behavior*, reflecting commitments to innovation and inclusion. However, significant gaps emerged—particularly the near-absence of *youth engagement*, and limited attention to *risk*, *security*, and *supply chain platforms*. Brazil and South Africa showed the broadest thematic coverage, while China and India were more narrowly focused. These findings highlight the need for more integrated, youth-conscious, and risk-aware narratives in shaping the future of fintech across emerging markets.

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A DESCRIPTION OF 'MORAL COMPETENCE' IN NURSING ACCORDING TO PATIENTS' AND NURSES' PERSPECTIVES: RESULTS FROM AN ITALIAN QUALITATIVE STUDY

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Abstract: There is a growing need for morally competent nurses to deal with increasingly complex situations and choices as encountered in professional daily life. However, there is no updated evidence about which characteristics, knowledge, skills, and attitudes a morally competent nurse should have and how to support their development. In the context of the EU-Erasmus+ funded project PROMOCON, this study aimed to describe the moral competences of nurses in Italy. A descriptive qualitative study was conducted, involving a purposeful sample of ten nurses and six patients' representatives in three focus groups. Findings were analyzed in an integrated manner using the content analysis. Nurses are morally competent when they provide personalised care, motivate the patients cared for, protect them in their choices, and set an example with their behaviour. They possess basic ethical, psychological, philosophical, humanistic and legal knowledge; they can understand and relate to others, not only patients/family members but also colleagues or students in difficulty by activating resources when necessary and being empathetic, patient, respectful, responsible, and flexible.

Keywords: nurses, moral competence, patient participation, focus groups, qualitative research

Descripción de la “competencia moral” en enfermería según la perspectiva de los pacientes y el personal de enfermería: resultados de un estudio cualitativo italiano

Resumen: Existe una creciente necesidad de enfermeras moralmente competentes para afrontar situaciones y decisiones cada vez más complejas, propias de la vida profesional diaria. Sin embargo, no existe evidencia actualizada sobre las características, conocimientos, habilidades y actitudes que debe poseer una enfermera moralmente competente ni sobre cómo apoyar su desarrollo. En el contexto del proyecto PROMOCON, financiado por la UE-Erasmus, este estudio tiene como objetivo describir las competencias morales de las enfermeras en Italia. Se realizó un estudio cualitativo descriptivo con una muestra específica de diez enfermeras y seis representantes de pacientes en tres grupos focales. Los hallazgos se analizaron de forma integrada mediante análisis de contenido, demostrando que las enfermeras son moralmente competentes cuando brindan atención personalizada, motivan a los pacientes que atienden, protegen sus decisiones y dan ejemplo con su comportamiento; poseen conocimientos éticos, psicológicos, filosóficos, humanísticos y legales básicos; pueden comprender y relacionarse con los demás, no solo con pacientes o familiares, sino también con colegas o estudiantes en dificultades, activando recursos cuando es necesario y siendo empáticas, pacientes, respetuosas, responsables y flexibles.

Palabras clave: enfermeras, competencia moral, participación de pacientes, grupos focales, investigación cualitativa

Uma descrição de “competência moral” em enfermagem de acordo com perspectivas de pacientes e enfermeira: resultados de um estudo qualitativo italiano

Resumo: Há uma crescente necessidade de enfermeiras moralmente competentes para lidar com situações e escolhas cada vez mais complexas como as encontradas na vida cotidiana profissional. Entretanto, não há evidência atualizada sobre quais características, conhecimentos, habilidades e atitudes, uma enfermeira moralmente competente deve ter e como apoiar seu desenvolvimento. No contexto do projeto PROMOCON, financiado pelo programa Erasmus da UE, esse estudo objetivou descrever as competências morais de enfermeiras na Itália. Um estudo descritivo qualitativo foi realizado, envolvendo uma amostra não probabilística de

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dez enfermeiras e seis representantes de pacientes em três grupos focais. Os achados foram analisados de uma forma integrada utilizando-se análise de conteúdo. Enfermeiras eram moralmente competentes quando elas forneciam cuidado personalizado, motivavam os pacientes cuidados, protegiam-nos em suas escolhas e davam um exemplo com seu comportamento. Elas possuíam conhecimentos básicos éticos, psicológicos, filosóficos, humanísticos e legais; elas podiam entender e relacionar-se com outros, não somente pacientes/membros da família como também colegas e estudantes em dificuldade, acionando recursos quando necessários, e sendo empáticas, pacientes, respeitosas, responsáveis e flexíveis.

Palavras chave: enfermeiras, competência moral, participação do paciente, grupos focais, pesquisa qualitativa

Introduction

Due to the challenges faced by healthcare systems all over the world, exacerbated by the pandemic, the staff shortage, and the change in patients' requirements, nurses and many other healthcare professionals are confronted with increasingly morally complex situations and choices(1). These challenges include delivering sub-optimal nursing care due to working in difficult environments with few nurses and internal (e.g., over different views on vaccination) or external (e.g., caring for sick people who are angry with the system) conflicts. Other challenges, which include, for example, the need to prioritize healthcare service access due to a lack of resources, are some of the issues that are calling for a reflection, also at the international level, upon the moral competences of nurses(2) and how to develop them(3).

Moral competence expresses the ability to recognise one's own emotions and values at stake that influence situations, reflect on them, and make a decision in the best interest of the person cared for(4). Moral competence is something that goes beyond ethical competence, which includes knowledge, skills, and abilities to handle specific ethical problems or dilemmas(5). The literature has long documented that morally competent nurses deliver care that is more attentive to people's needs, values, and principles(3,6). However, despite the efforts(7) devoted by nursing programs and professional mandates(8,9), also in line with the European directives that have just reaffirmed the need to train nurses on these aspects(10), there are still no guidelines on how to prepare nurses and how to support them(11). Furthermore, it is recommended that research approaches should go beyond the professional perspective, preventing the tendency to self-define the expected moral competences, in order to also consider that of the main stakeholders, i.e., patients receiving nursing care(8). Updating comprehension about the characteristics, knowledge, skills and attitudes that morally competent nurses should possess, as well as strategies to support their development, would help educators and professional bodies to advance lines of action.

To bridge this knowledge gap, a qualitative study was conducted to describe the moral competences

that nurses should possess on the basis of the views and perspectives of nurses and patient representatives.

Methods

Design

A descriptive qualitative study using focus groups to collect data(12) was conducted as part of European Erasmus funded project called PROMOCON (PROmoting a MORally COmpetent Nurse) (<https://promocon.upatras.gr/en/>). In the reporting phase, the guidelines Consolidated Criteria for Reporting Qualitative Research (COREQ) were followed(13).

Participants and Setting

Purposeful sampling was employed(14): three groups of a total of 16 participants were formed and the whole process (e.g., the interview analysis guide) followed a plan previously designed to assure the validity and reliability of the data.

In the first focus group, three volunteer nurses piloted the interview guide: they confirmed the comprehensibility of the questions without requesting any changes. In the second focus group, a group of practicing nurses from different care settings and who wished to participate were involved; support workers or professionals not in an active role were not eligible. Finally, in the third focus group, representatives of patient associations, who were either chairpersons or members and who wished to participate, were involved: those recruited by the health service (e.g., for outpatient treatments) or involved in the care of family members at the time of the study were not eligible. Sampling sought to ensure maximum heterogeneity of participants by ensuring five to nine participants per focus group(12).

Data Collection

All participants, who had had previous collaborations with the university and were known by researchers for their interest in ethical issues, were contacted by telephone: they were asked to participate after having been informed of the aims of the project and the method of data collection. Everyone signed up and filled in a demographic

data collection form. The focus groups were held in a room on the university campus in a quiet and confidential setting. A moderator (a nurse with a PhD who is an expert in qualitative research) led the group by asking questions

, and an observer (a nurse with a master’s degree, from a clinical setting) took some notes and observed non-verbal behaviours. Participants knew neither the moderator nor the observer. After the introductory phase, the guiding questions (Table 1) were asked.

The focus groups lasted approximately two hours each and were audio-recorded and transcribed verbatim. After three focus groups (one with patient representatives, two with nurses) the data appeared saturated(15) and the researchers decided to conclude the interviews. Repeated interviews to verify or better explore certain topics were not conducted; the transcripts and/or analyses of the focus groups were not returned to participants.

Table 1. Focus group questions

<i>Introductory warm-up and contextualisation questions</i>	
-	With respect to the concept of ‘moral competence of nurses’, what situations or experiences come to mind? This seems very positive (if the examples are positive) or negative (if the examples are negative). What other opposite experiences have you had?
-	Which morally ‘difficult’ situations involving nurses have you experienced or witnessed? Can you describe them?
<i>Specific questions consistent with the aims of the study</i>	
1.	What do you mean by ‘morally competent nurse’? How would you define a ‘morally competent nurse’? What are their main characteristics?
2.	In your opinion, what
-	knowledge
-	skills/competences
-	attitudes
	must nurses demonstrate in clinical practice in order to be considered ‘morally competent’?
3.	In your opinion, how should nurses be supported to develop their moral competence?
<i>Closing questions</i>	
-	Is there anything else you would like to share?

Data Analysis

Data analysis was conducted following a content analysis approach(16). After the transcription of the focus groups, two researchers jointly identified the most significant sentences. From these, the most important concepts representing them were highlighted. The coding process followed the three main research questions: (a) general characteristics of a morally competent nurse, (b) main components of nurses’ moral competence, and (c) tools or methods needed to support it. The data from the three focus groups (N, concerning nurses, R concerning patient representatives) were analysed manually by the researchers (see authors), first separately and then integrating them, highlighting similarities and differences.

The rigor of the study was assured through a set of three criteria for assessing qualitative research: credibility, transferability, and dependability. Credibility aims to demonstrate that the study was conducted in a way that ensured a rigorous description of the phenomenon under study. This was achieved by taking field notes and triangulation of data analysis through verification and discussion with all researchers. Transferability refers to the applicability of the findings to similar contexts or situations. This was accomplished by providing sufficient details and in-depth descriptions of participants’ experiences. Finally, dependability shows that the findings could be repeated. This was ensured with the help of outside reviewers, who supervised the entire process.

Ethical Considerations

The project was approved by the Institutional Review Board of the University of Udine, Italy (Ref No 33/2023). Participants were free to participate and could withdraw from the study at any time without repercussions. All results were anonymised so that participants and the examples they reported could not be identified.

Results

Characteristics of participants

Ten nurses and six representatives of patients’ associations were involved. The professional focus

Table 2. Focus groups: characteristics of participants

Nurses' focus group							
ID	Gender	Age	Qualification	Role	Experience (years)	Current setting	Current setting (years)
1	Female	26	Bachelor's Degree	Clinical nurse	3.5	Hospital	1.5
2	Male	38	Bachelor's Degree	Academic tutor	15	University ^a	1
3	Female	24	Bachelor's Degree	Clinical nurse	2.5	Hospital	2.5
4	Female	38	Master's Degree	Academic tutor	14	University	2
5	Male	48	Diploma	Nurse coordinator	23	Hospital	0.4
6	Male	23	Bachelor's Degree	Clinical nurse	0.4	Hospital	0.4
7	Female	47	Diploma	Nurse coordinator	23	Territory	7
8	Male	41	Master's Degree	Academic tutor	14	University	8
9	Female	28	Master's Degree	Clinical nurse	3.5	Hospital	3
10	Male	30	Bachelor's Degree	Clinical nurse	1	Territory	1
Patient protection associations' focus group							
ID	Gender	Age	Qualification	Association	Experience as		
					patient	caregiver	
1	Female	33	High School Diploma	Tribunale dei diritti dei malati (Patients rights tribunal)	No	No	
2	Female	38	University Degree	Associazione Italiana contro Leucemie, linfomi e mieloma (Italian Association against Leukemia, Lymphoma and Myeloma)	Yes	No	
3	Female	53	High School Diploma	Associazione Donatori di Midollo Osseo (Bone Marrow Donor Association)	No	Yes	
4	Female	65	High School Diploma	Associazione Nazionale Donne Operate al Seno (National Association of Breast Operated Women)	Yes	No	
5	Female	41	University Degree	Associazione Donatori di Midollo Osseo (Bone Marrow Donor Association)	Yes	Yes	
6	Female	39	University Degree	Tribunale dei diritti dei malati (Patients rights tribunal)	No	No	

^aLecturer in ethics

groups (Table 2) were composed of clinical nurses, academic tutors (of whom one was a lecturer in ethics) and ward managers with an average age of 34.3 years and a professional experience of approximately 10 years. Half were female and the majority possessed a nursing degree. The representatives of patients' associations were women, aged from 33 to 65 years, with a high school diploma or a university degree; some had lived experiences as patients and/or caregivers (Table 2) and represented associations with different aims.

The profile of a morally competent nurse

According to participants, morally competent nurses possess four visible characteristics that must be co-present:

They deliver personalised care: they can put the person at the centre, delving into their values, needs and situation; on such basis, they can offer 'tailored' care.

"So, in my opinion, morally competent nurses are nurses who can understand the situations they are in, to understand all the values at stake within that

particular situation and, let's say, understand what is best So, they're able to identify all the facets of the situation and grasp the values of the person and take them into account in the care to be provided." (N3)

"...tailor care to the patient's situation ... put the person at the centre by personalising care." (R4)

They motivate the person cared for, identifying the resources they can use to achieve the maximum degree of autonomy; they activate all possible strategies, encouraging patients to have confidence in their resources and to mobilise them.

"... they search where the resource is, pull it out to enable people in whatever setting they are, that is at home, in a hospital and on the territory, to be able to cope with what is happening to them. So, for me, competence and the ability to bring out the best of what's there, despite the moment." (N2)

"... they identify people's needs and understand what the patients' latent and residual resources are, to bring them to the maximum degree of autonomy in dealing with their illness." (R2)

They protect the people cared for and their right to make their own choices: even if at times these choices are not agreeable or understandable, morally competent nurses ensure full freedom of choice by supporting patients in their decisions.

"... be able to assist without judging and without 'influencing the patient's decisions' even if they are not in line with ... one's own convictions about the correctness of the situation one finds oneself in." (N2)

"I would include the ability to protect the person here." (R2)

They set an example with their behaviour both for the people cared for and their colleagues, especially the younger ones. In this way, they inspire other professionals, becoming a point of reference.

"And then excellence, in order to differentiate it from a standard competence, must necessarily be catalytic, i.e. nurses who are excellent on a moral level are nurses who drag others behind him/her, who also inspire colleagues and who also act as a reference for patients. And they do not necessa-

rily do this in their extra time as we were saying, of course, the pandemic situation has exacerbated the lack of time to devote to the care relationship, but probably ethically excellent nurses manage to make up for these moments precisely by optimising time." (N6)

"... let's say that the nurse is the closest link to the patient and therefore a point of reference..." (R6)

Knowledge, skills/behaviours, and attitudes of a morally competent nurse

Participants agree on the need for basic education, including philosophy, ethics, psychology, humanistic lessons – to understand the role of cultural differences in nursing practice – and legal aspects (e.g., Advance Healthcare Directives) (Table 3). Some skills were indicated by both focus groups, while others were indicated only by nurses. Both found morally competent a nurse who can (a) understand situations, needs and contexts: this means showing an understanding not only of what is going on, but also of the values involved, the responses of patients and family members/caregivers; (b) listen to and communicate not only with the sick person but also with the family, using appropriate and understandable words, establishing a close contact. To these, nurses also added the ability to (c) identify priorities, discuss issues with colleagues, and promote the activation of resources (e.g., ethics committees for clinical practice or peer ethics counseling) to delve into situations about which there is disagreement and for which broader discussion is needed; (d) support those who are in distress, whether they are students or colleagues.

Attitudes were instead described homogeneously by nurses and representatives of patients: the attitude for reflection and for asking oneself the right questions, to discover oneself and the others, to delve into situations, to know one's limits and to avoid errors generated by standard answers, was considered to be essential; the same applies to reflexivity, which makes nurses aware of their own needs for training or help when situations are very challenging or cannot be handled with the available knowledge and skills. Flexibility, which expresses the ability to adapt while keeping one's underlying principles intact, was also considered

Table 3. Knowledge, skills, and attitudes of a morally competent nurse

Knowledge	N	R	Quotes
<i>Philosophical, psychological, ethical</i>	x	x	“Definitely philosophy and ethical theories, both at the bachelor's and master's degree level, but especially at the bachelor's level because not everyone then continues their studies...” (N3) “Then in my opinion for them I would also do some philosophical practices.” (R5)
<i>Humanistic/cultural</i>	x	x	“...to understand the differences and have the basis for understanding.” (N2) “...to take into consideration behaviors or cultures different from our own because we will be dealing with diversity more and more.” (R3)
<i>Legal</i>	x	x	“...knowledge of the normative context within which we move because some situations require decisions that also have a normative framework e.g. Advance Healthcare Directives and the whole euthanasia discourse...” (N3) “If I have to think of the first thing that comes to mind, it's actually the normative framework.” (R5)
Skills	N	R	Quotes
<i>Interpreting situations and contexts</i>	x	x	“Maybe even knowledge of the context, in which I'm moving. Because in the end you know it by being in it. Like also the knowledge of the patient, going back to the example you were making: yes, cigarettes hurt but if I know that to him, in a context where I can allow to let it ring...” (N9) “...reflecting is something that allows you to interpret the situation and thus relate to the other and promote the enhancement of the individual person.” (R2)
<i>Listening</i>	X	x	“And listening to the caregiver or those close to the patient, to understand facets that the patient cannot express.” (N2) “Listening to each other.” (R3)
<i>Communicating</i>	x	x	“And I happened to, precisely, care for a pre-term infant with very experienced nurses from my department even if at times some resuscitations go wrong or we fail to, let's say, get the infant to survive, the way the communication to the family is then handled, the way the woman, the couple and let's say the family is actually cared for, now with covid they are able to get relatives in as well, in my opinion this is a great moral competence of my experienced colleagues.” (N3) “...because communication is fundamental at any time of life, in any sphere.” (R1)
<i>Identifying priorities</i>	X		“Contextualize the decision on priorities, for one patient one aspect is a greater priority than for others. So, in my opinion, this aspect is not the same for everyone, so it is prioritized for certain patients.” (N4)
<i>Discussing with/within the team</i>	X		“...a skill that all professionals will need to have. Discussions among peers, as well as within teams, to reflect upon what needs to be done or what could have been done or not.” (N4)
<i>Activating resources</i>	X		“Committees, rather than case discussions among various specialists, to understand the various possible solutions, in short, to be brought to the patient as well.” (N2)
<i>Supporting colleagues/students in distress</i>	X		“...always accompanying them and showing support to students and colleagues in particularly difficult situations.” (N3)
Attitudes	N	R	Quotes
<i>Asking oneself questions</i>	x	x	“...doubt, questions, placing oneself in a horizon not made of certainties, but actually of fluidity. The attitude is always based on

			discovering each other, on not taking anything for granted, on...having references maybe...even important ones, however always with a doubt..." (N7) "I see them as doubtful people, meaning that they ask themselves questions with respect to what they are doing or experiencing." (R3)
<i>Reflexivity</i>	x	x	"... it is necessary to reflect, to have a good deal of patience, ... to be calm and quiet in the situation in order to move forward..." (N2) "...I would add patience." (R2)
<i>Flexibility/adaptability</i>	x	x	"...sometimes it is necessary to change attitude and way of thinking as situations or opportunities change." (N5) "... adaptable while keeping their underlying principles... er... strong here, in short. References...not to get lost in that flexibility." (R4)
<i>Dedication</i>	x	x	"showing commitment to things, to issues ... devoting time to patients, but also to the team ..." (N7) "...an attitude toward the other..." (R4)
<i>Assuming responsibilities</i>	x	x	"...take responsibility for choices...take responsibility for the choice..." (N5) "...to know how to take charge of the person's problems, that is, to feel responsible, without stopping at mere performance or compartmentalization." (R4)

Legend: N, Nurse; R, Representative of patients' association.

Table 4. Tools or methods supporting nurses in the development of ethical knowledge, skills and attitudes

Tools/methods	N	R	Quotes
<i>Education</i>	x		"Because while you were asking the question the education came to my mind, starting from the basics first of all." (N7)
<i>Stimuli for ongoing reflection</i>	x		"... being helped to continually reflect ... an effort, a stimulus ... to wonder and think about what is happening ..." (N8)
<i>Integration among professionals</i>	x	x	"And so the integration among professions whether it's physicians, or even the social and health workers that we don't include many times ...in teams ...a shared training and shared values." (N3) "...a team made of people who are there because they want to be there, that helps." (R2)
<i>Spaces for sharing</i>	x	x	"And then perhaps in creating spaces for sharing." (N7) "...these spaces also become a protective support from a moral point of view" (R2)
<i>Receiving confirmation: social recognition</i>	x	x	"This in some ways is a sign of recognition of the citizens, of the people we care for, towards nurses. It was felt so much with COVID, they were always talking about nurses. Now already a little less. That is probably one of the most motivating factors probably from this point of view for nurses, because they feel that their work, their profession, is useful and recognized by people. So definitely the social recognition of the profession." (N2) "...to be recognized and seen for one's inclinations, to have the opportunity to develop them, and then to be placed in a context where you can give the best of yourself, giving satisfaction to the others, because in any case ours is a helping profession, that we are fulfilled when people 'are feeling better.'" (R2)

Legend: N, Nurse; R, Representative of the association.

essential. Finally, the focus groups found morally competent those nurses who show dedication, commitment to what they do, and who assume the responsibilities associated with their role.

Strategies to support the development of nurses' moral competences

According to nurses, moral competence needs to be developed in basic and continuing education. Such education should be tailored to the problems faced by the nursing profession and updated to the most current issues. Being able to rely on continuous stimuli for reflection offered by colleagues, coordinators, and students is another essential strategy to promote the attitude of asking oneself questions and learning from experience.

Patients and nurses feel that opportunities for integration among professionals, where they can work together, understand the multidimensional nature of problems and address them each with their own perspectives, are important. These spaces and times for sharing (between nurses, between nurses and physicians, between teams and patients/families) should be recognized and not relegated to free time. Support should also be provided from the outside, through social recognition: when the profession is recognized, nurses are encouraged to invest in their own competences, including moral ones.

Discussion

This study aimed at filling knowledge gaps by exploring the characteristics, knowledge, skills and attitudes that a nurse should possess in order to be considered as morally competent, integrating the patients' perspective. In addition, the study aimed to explore the "softer" skills of care, including attributes and personality traits, in an era in which technological skills are prevailing, leaving less space to more humanistic and compassionate approaches: defining these competences is considered a prerogative of such professions, especially in this challenging period, where some changes in the moral profile can be occurring. Moreover, having included patient representatives allowed a comprehensive view by giving voice to their daily experiences(17). Indeed, the 'emic perspective', i.e., that of stakeholders was included, considering

that moral competences cannot be understood without considering cultural and social contexts, subjective experiences, values, and meanings that people assign to these competences. Integrating the two perspectives ensures the creation of values focusing also on the protagonists of care, namely the patients(18).

The profile that emerged with respect to the morally competent nurse included several dimensions. In particular, the four characteristics express a professional and a relational dimension. Knowing how to deliver individualized care is considered to be an expression of moral competence because it leads nurses to search for data and knowledge about those for whom they are caring, their values and preferences(19, 20). 'Motivating', 'protecting' and 'setting an example', on the other hand, express the relationship with both patients and colleagues, confirming that nursing care is first and foremost an encounter between human beings(21). These characteristics support the understanding of the moral stress experienced by nurses when they cannot act consistently with expectations due to a lack of time, toxic or hostile work environments(11). In addition, these characteristics express a performance that is visible not only to the nurses themselves but also to patients and their families, and on which it is needed to activate reflections, strategies and support concerning their continuous development, when it results to be suboptimal performance.

The knowledge that nurses should possess is not described in detail: participants mention philosophical, ethical, psychological, humanistic, and legal disciplines without, however, dwelling on the content. These are subjects generally offered by the nursing program, although their harmonization with respect to credits, learning objectives, teaching methodologies and expected outcomes would be needed, considering that overall, at the European level, our students are found to be poorly prepared on such dimensions, as technical-procedural aspects tend to be privileged(8).

Among the skills, those related to understanding and the relationships with others were highlighted in both focus groups: in line with the literature, moral competence requires skills to protect the vulnerability of others through moral sensitivity,

interactions, and flexibility(22). All these aspects were presented by the participants as linked to an 'empathetic' nurse. Such skills should be part of explicit nursing student preparation and assessment systems, as well as of ethical codes(9). Nurses suggest additional skills towards colleagues or students in distress, which are in fact the same skills they should develop in favor of patients, but focused on colleagues: the ability to ask for help and to activate resources to be supported in overcoming problems/difficulties through group or expert advice. While on the one hand it is understandable that patient representatives do not report these skills, which are taken for granted or are less visible to them, on the other hand this 'internal care' within the group towards those in distress, or as the ability to ask for help when in distress, is in line with the literature that emphasizes the importance of the work environment and climate in preventing moral stress(23). Moral competence involves sensitivity towards others – not exclusively towards patients; colleagues may also need support. Moreover, as it specifically activates each of us in putting our values/beliefs on the line, it can turn us into people who need help in nursing care: being able to rely on a group or hospital resources made available to deliver support can make all the difference. Among skills, nurses also point out the ability to identify priorities: choosing what to do first or next, and especially what to neglect – in times of resource scarcity, is a decision that has moral implications. Differences in prioritization can generate conflicts among nurses, confusion among patients, and loss of care deemed essential for some and less so for others (e.g., relationship)(24).

Finally, the two focus groups of nurses agree on attitudes, describing a nurse who is continuously learning, shows dedication, and demonstrates a willingness to take responsibility. The literature, too, has repeatedly underlined the need for nurses to be reflective practitioners(25): on the one hand, such attitudes nurture moral competence and, on the other, they express it visibly. Teaching them to be reflective should be a priority in our education systems – sometimes too procedure- and technique-oriented(8).

The strategies suggested to support the moral competence of nurses are the typical ones (training

and teamwork) already reported in the literature(3,26); however, these strategies should rely on a formal space, valued by hospitals and recognized. Continuing education or reflection on practice does not always take place during duty hours; nurses are often required to use their free time for these development activities. Being recognized as valuable professionals, moreover, is considered to provide important support, as it encourages continuous deepening(27); organizations and society need to understand that investing in continuous education and support of the nursing personnel, who spend more time than any other professional near the patient, will benefit them and promote their safety and well-being.

Limitations

The study has several limitations. Nurses and representatives of patients' associations linked to researchers' context were included: additional focus groups at the national level could broaden this perspective. Furthermore, including more patients' associations that also reflect other health issues could ensure a more comprehensive view. Keeping the two focus groups separate facilitated free discussion by participants, who were likely to feel comfortable; however, a single focus group may further develop the understanding of the matter and provide integrated results. Finally, from a conceptual point of view, moral and ethical competence were not divided in their meaning, but considered as a broader conceptualization.

Conclusions

We conducted a qualitative study where two different perspectives were combined: that of nurses and that of the representatives of patients. Overall, the emerging profile is that of a nurse capable of fully developing the professional and relational competences expected in the scope of practice. When it comes to knowledge, skills and attitudes that nurses should possess to be morally competent, it became clear that they all revolve around three important concepts: communication, understanding and relationships with others. The development of moral competences should be continuously promoted with appropriate tools, as formal continuing education, on-the-job spaces for reflection and hospital services devoted to supporting nurses

in dealing with critical issues/dilemmas; however, social recognition has also been identified by both groups as capable of promoting moral competence. Being recognized by society promotes a feeling of respect towards nurses, thus encouraging them to keep developing their competences, including moral ones.

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ATTITUDES OF HEALTHCARE WORKERS TOWARDS DISABLED WOMEN, AFFECTING FACTORS AND ETHICAL DIMENSION: A DESCRIPTIVE AND CROSS-SECTIONAL STUDY

Meltem Akbaş¹

Abstract: This study was conducted descriptively and cross-sectionally to determine the attitudes of healthcare professionals towards disabled women, the factors affecting them, and to evaluate their ethical dimensions. This descriptive study was conducted between 08/01/2022 and 10/31/2022 with midwives, nurses, and doctors working at the hospitals in Kahramanmaraş/Turkey. The sample size of the study was calculated with G*Power, and 307 healthcare professionals were included in the study. The research data were collected with the Personal Information Form and the Disabled Woman Attitude Scale. The data were analyzed with the SPSS for Windows 22.0 statistical package program. The total mean age of the participants was 33.60 ± 7.51 , the mean score of the disabled women and their private lives sub-dimension was 23.97 ± 5.72 , the mean score of the disabled women and disadvantages sub-dimension was 12.68 ± 4.37 , the mean score of the disabled women and social support sub-dimension was 14.88 ± 3.33 , the mean score of the disabled women and gender sub-dimension was 9.33 ± 3.18 and the total mean score of the scale was 60.87 ± 13.17 . In this study, it was observed that the attitudes of health workers towards disabled women were positive and that receiving training for disabled individuals and gaining experience in the care and treatment of disabled individuals positively affected the attitudes towards disabled women.

Keywords: disabled woman, doctor, ethics, midwife, nurse

Actitudes de los profesionales de la salud hacia las mujeres con discapacidad, factores que las afectan y dimensión ética: un estudio descriptivo y transversal

Resumen: Este estudio se realizó de forma descriptiva y transversal para determinar las actitudes de los profesionales de la salud hacia las mujeres con discapacidad y los factores que las afectan, y evaluar sus dimensiones éticas. Este estudio se llevó a cabo entre el 1 de agosto y el 31 de octubre de 2022 con matronas, enfermeras y médicos que trabajaban en los hospitales de Kahramanmaraş, Turquía. El tamaño de la muestra del estudio se calculó con G*Power, e incluyó a 307 profesionales de la salud. Los datos de la investigación se recopilaron con el Formulario de Información Personal y la Escala de Actitudes hacia la Mujer Discapacitada. Los datos se analizaron con el programa estadístico SPSS para Windows 22.0. La media de edad total de las participantes fue $33,60 \pm 7,51$; la de la subdimensión mujeres discapacitadas y su vida privada fue $23,97 \pm 5,72$; la de la subdimensión mujeres discapacitadas y desventajas fue $12,68 \pm 4,37$; la de la subdimensión mujeres discapacitadas y apoyo social fue $14,88 \pm 3,33$; la de la subdimensión mujeres discapacitadas y género fue $9,33 \pm 3,18$, y la media total de la escala fue $60,87 \pm 13,17$. En este estudio se observó que las actitudes de los trabajadores de la salud hacia las mujeres con discapacidad fueron positivas y que recibir formación sobre discapacidad y adquirir experiencia en el cuidado y tratamiento de personas con discapacidad afectaron positivamente las actitudes hacia las mujeres con discapacidad.

Palabras clave: mujer con discapacidad, médico, ética, matrona, enfermera

Atitudes de trabalhadores de cuidados à saúde em relação a mulheres com deficiências, fatores que influenciam e dimensão ética: um estudo descritivo e transversal

Resumo: Esse estudo foi realizado descritivamente e transversalmente para determinar as atitudes de profissionais de cuidados à saúde em relação a mulheres com deficiências, os fatores que as influenciam e avaliar suas dimensões éticas. Esse estudo descritivo foi realizado entre 01/08/2022 e 31/10/2022 com parteiras, enfermeira e médicos trabalhando nos hospitais em Kahramanmaraş, Turquia. O tamanho amostral do estudo foi calculado com G*Power e 307 profissionais de cuidados à saúde foram incluídos no estudo. Os dados da pesquisa foram coletados com o Personal Information Form e a Disabled Woman Attitude Scale. Os dados foram analisados com o programa do pacote estatístico SPSS for Windows 22.0. A idade média dos participantes foi $33,60 \pm 7,51$, o escore médio das mulheres deficientes e sua subdimensão vidas privadas foi $23,97 \pm 5,72$, o escore médio das mulheres deficientes e sua subdimensão prejuízo foi $12,68 \pm 4,37$, o escore médio das mulheres deficientes e sua subdimensão apoio social foi $14,88 \pm 3,33$, o escore médio das mulheres deficientes e sua subdimensão gênero foi $9,33 \pm 3,18$ e o escore médio total da escala foi $60,87 \pm 13,17$. Nesse estudo observou-se que as atitudes de trabalhadores de cuidados à saúde em relação a mulheres com deficiências foram positivas e que receber treinamento para indivíduos com deficiência e adquirir experiência no cuidado e tratamento de indivíduos com deficiência afetou positivamente as atitudes em relação a mulheres com deficiência.

Palavras chave: mulheres deficientes, médico, ética, parteira, enfermeira

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Introduction

Disability is a condition that is congenital or acquired, significantly restricts an individual's life functions for any reason and also affects physical, mental, psychological, and social reasoning(1). With the increase in the world population, and chronic diseases, the disabled population is also increasing day by day. While the ratio of disabled people to the world population is estimated to be 15%, it is reported that 80% of disabled people live in developing countries(2,3). According to the results of a comprehensive research conducted in 2002 on disability in our country, 12.29% of the total population consists of disabled individuals(4). In the 2015 report of the Türkiye Statistical Institute (TUSI), it was reported that the rate of disabled people is 5.9% for men and 7.9% for women(5). According to the report published by the Prime Ministry Disabled People Administration, it was stated that the ratio of female disabled individuals to the total population is 13.4%, 44.5% of disabled women are married and 40% are of reproductive age(4).

Disabled individuals constitute a disadvantaged group in society. Disabled women are exposed to both the negative situation stemming from being disabled and the disadvantages and gender discrimination brought by being a woman(6,7). It is reported that female disabled individuals have lower rates of participation in education and work life and utilization of health care services compared to men, the level of poverty is higher(2).

Disabled women need more support, education and care from health personnel than male disabled individuals due to their reproductive functions. In addition, pregnancy planning, the pregnancy process, birth and the postpartum period are of special importance for these women (8). However, many physically disabled women cannot access the health services they need due to various obstacles such as environmental and physical limitations, lack of education and economic difficulties(9,10). Disabled women not only face financial and physical obstacles in accessing health services, but also are exposed to discriminatory and disrespectful behaviors of health workers. A systematic review of qualitative studies to determine the barriers that women

with disabilities face in accessing health services revealed that these women face a variety of sociocultural (incorrect assumptions, negative attitudes, being ignored, being judged, violence, abuse, insults, rudeness, and low health literacy), financial (poverty, unemployment, high transportation costs), structural (lack of insurance coverage, inaccessible equipment and transportation, lack of information, lack of access to information, lack of transparency), and communication problems(11). When evaluated ethically, the attitudes of health professionals towards women with disabilities should be considered from a human rights perspective. Access to health services for women with disabilities requires an approach based not only on physical treatment but also on psychosocial support and social equality(12). In this context, the attitudes of health professionals must be shaped by respecting the dignity and independence of individuals with disabilities. The ethical responsibilities of healthcare professionals in the care of disabled women should include not only physical recovery but also supporting the individual's social role, identity, and sense of self(13).

The attitudes of health workers should be developed based on professional codes of ethics, ethical principles, and an empathetic approach, as these attitudes will facilitate the access of women with disabilities to health services while also contributing to the adoption of a more equitable approach in society.

The attitudes of healthcare professionals towards disabled women are very important in disabled women's application to healthcare institutions and in receiving quality healthcare services. The people closest to disabled women are healthcare professionals. There are studies in the literature examining the attitudes of students studying in the field of health and healthcare professionals towards disabled individuals(14-18). However, no study has been found in which the attitudes of healthcare professionals towards disabled women, the factors affecting them, and the attitudes of healthcare professionals towards disabled women are investigated and their ethical dimensions are discussed together. In this context, it is thought that our study is original and will make a positive contribution to the literature, disabled

women and health workers. In this context, it is thought that our study is original and will contribute positively to the literature, disabled women and healthcare professionals.

Aim

This study was conducted to determine the attitudes of health care workers towards women with disabilities and the influencing factors and to evaluate the ethical dimension of the attitudes of health care workers towards women with disabilities.

Research questions

1. What are the attitudes of healthcare professionals towards disabled women?
2. What factors affect the attitudes of healthcare professionals towards disabled women?
3. What is the ethical dimension of the attitudes of healthcare professionals towards disabled women?

Methods

Type of the research

This research is a descriptive and cross-sectional study.

Place and time of the research

The study was conducted between 01.08.2022 and 31.10.2022 in Kahramanmaraş, City Hospital, State Hospital and Maternity and Children's Hospital located in southeastern Turkey.

Universe and sample of the research

The universe of the research consists of 1518 midwives, nurses and doctors working in the relevant hospitals. The sample size universe of the research was calculated using the known sample calculation formula. As a result of the calculation, the sample size was determined to be 307, and the study was conducted with 307 midwives, nurses and doctors. Healthcare workers who agreed to participate in the study, health care workers who worked in the hospital where the study was

conducted and who agreed to participate in the study were included in the study. Healthcare workers who were on leave, on sick leave, working in another institution with an assignment during the data collection period, who gave inconsistent answers and who did not want to participate in the study were not included in the study.

Data collection tools

The data in the study were collected with the Personal Information Form, which questions the socio-demographic characteristics of the participants and the Disabled Woman Attitude Scale (DWAS).

The personal information form was prepared by the researchers by reviewing the literature(19-22). It consists of a total of 12 questions, including personal information (9 questions) and the status of being a relative of a disabled person, their status of receiving education regarding the care of disabled individuals, and their experiences regarding the care and treatment process (4 questions).

DWAS is a scale that determines the attitudes of healthcare professionals and students towards disabled women. DWAS is a 5-point Likert-type scale consisting of 17 items and 4 factors developed by Yılmaz and Ören (2021)(23). Each item in DWAS is scored from 1 to 5. The statements were asked to be rated between 1 (strongly agree) and 5 (strongly disagree). The number 1 indicates high negativity towards completely agreeing, and the number 5 indicates completely disagree indicates low negativity. The lowest score received from DWAS is 17, and the highest score is 85. A low score indicates high negativity for disabled women, while a high score indicates low negativity. The Cronbach's alpha value of the scale was found to be 0.817 and the test-retest correlation value was found to be 0.992(23). In this study, Cronbach's alpha coefficient was found to be 0.91.

Data collection

Data were collected by the assistant researcher using the face-to-face interview method. Before the survey was administered, the health worker was informed about the study and written and

verbal consent was obtained. The surveys were filled out at the participants' convenience and took an average of 10 minutes.

Analysis of the data

Data were analyzed using the Statistical Programme for Social Science 22.0 (SPSS) program. In the analysis of the study, frequency, percentage, mean, and standard deviation statistical methods were used as descriptive statistics. The Shapiro-Wilk test was performed and it was determined that the data did not show normal distribution. Since the data did not show a normal distribution, analysis was performed with nonparametric tests. In the comparison of dependent and independent variables, the Mann-Whitney-U test was used to evaluate the difference between the means of 2 groups, and the Kruskal-Wallis test was used to evaluate the difference between the means of 3 or more groups. The statistical significance value was taken as $p < 0.05$.

Ethics approval and consent to participate

The research was approved by Cukurova University Faculty of Medicine Non-Interventional Clinical Research Ethics Committee on June 2022, 50/3. Institutional permission from the hospitals; written and verbal informed consent was obtained from the participants. Permission to use the scale has been obtained. The study was carried out in accordance with the Declaration of Helsinki.

Findings

The socio-demographic characteristics of the healthcare workers participating in the study are shown in Table 1. Accordingly, the average age of the healthcare workers was 33.60 ± 7.51 (min:24, max:60), 52.8% were 31 years old and above, 77.2% were female, 59.3% were married, 52.8% had children, 73.0% were nurses, 52.8% had a bachelor's degree, and 59.0% had worked for 6 years or more. It was also determined that 70.7% did not have a disabled relative, 53.7% did not receive training on the care of disabled individuals during their education, 73.3% did not receive in-service training on the care of disabled individuals while working, 90.2% did not receive training to facilitate communication with

disabled individuals or caregiving, and 65.1% did not have experience in the care, monitoring or treatment of disabled individuals (Table 1).

Table 1. Descriptive Characteristics of Healthcare Workers (N: 307)

Descriptive Characteristics	n	%
Age average 33.60 ± 7.51		
30 years and below	145	47.2
31 years and above	162	52.8
Gender		
Female	237	77.2
Male	70	22.8
Marital status		
Married	182	59.3
Single	125	40.7
Children		
No children	145	47.2
Have children	162	52.8
Occupation		
Physician	27	8.8
Midwife	56	18.2
Nurse	224	73.0
Educational status		
High school-Associate degree	97	31.6
Undergraduate	162	52.8
Postgraduate	48	15.6
Working period		
5 years and below	126	41,0
6 years and above	181	59,0
Having a relative with a disability		
Yes	90	29.3
No	217	70.7

Having received training on caring for disabled people during education		
Yes	142	46.3
No	165	53.7
Having received in-service training on caring for disabled people while working		
Yes	82	26.7
No	225	73.3
Having received training to communicate with disabled people or to facilitate caring for them		
Yes	30	9.8
No	277	90.2
Having had experience in caring for, monitoring or treating disabled individuals		
Yes	200	65.1
No	107	34.9

Table 2 shows the distribution of the participants' mean scores from the DWAS and its sub-dimensions. It was determined that the health workers' mean DWAS women with disabilities and their private lives sub-dimension score was 23.97 ± 5.72 , their mean disabled women and disadvantages sub-dimension score was 12.68 ± 4.37 , their mean disabled women and social support sub-dimension score was 14.88 ± 3.33 , their mean disabled women and gender sub-dimension score was 9.33 ± 3.18 , and their mean total scale score was 60.87 ± 13.17 (Table 2).

Table 2. Distribution of mean scores of healthcare professionals from DWAS and its sub-dimensions (N: 307)

DWAS and Sub-dimensions	Min	Max	X $\pm$ SD
Disabled Women and Their Private Lives	6	30	23.97 ± 5.72
Disabled Women and Disadvantages	4	20	12.68 ± 4.37
Disabled Women and Social Support	4	20	14.88 ± 3.33
Disabled Women and Gender	3	15	9.33 ± 3.18
DWAS Total Score	17	85	60.87 ± 13.17

X: Average, SD: Standard Deviation, Min: Minimum, Max: Maximum.

When the DWAS subdimensions and total scores of the participants were compared according to the sociodemographic characteristics, it was determined that there was a significant difference between the participants' ages and disabled women and private lives, disabled women and social support subdimensions, between occupation and disabled women and social support, disabled women and gender subdimensions, between educational status and disabled women and social support, disabled women and gender subdimensions, and between years of employment and disabled women and gender subdimensions ($p \leq 0.05$). Between the status of receiving training on the care of disabled people during education and disabled women and private lives, disabled women and disadvantages, disabled women and social support, disabled women and gender subdimensions and DWAS total score; between the status of receiving in-service training on the care of disabled people while working and disabled women and social support, disabled women and gender subdimensions and DWAS total score; It was determined that there was a significant difference between the status of receiving education that will facilitate communication or caregiving

Table 3. Distribution of DWAS total and sub-dimensions mean scores of healthcare workers according to their descriptive characteristics (N: 307)

Descriptive Characteristics	DWAS				
	Disabled women and their private lives	Disabled women and disadvantages	Disabled women and social support	Disabled women and gender	Total
	X±SD	X±SD	X±SD	X±SD	X±SD
Age					
30 years and below	25.05±5.05	12.91±4.44	15.32±3.16	9.20±3.18	62.49±12.15
31 years and above	25.05±5.05	12.48±4.31	14.48±3.43	9.45±3.19	59.43±13.91
p	0.002	0.462	0.020	0.316	0.061
Z	-3.031	-.735	-2.333	-1.002	-1.875
Gender					
Female	23.86±5.88	12.84±4.37	14.93±3.37	9.46±3.23	61.10±13.50
Male	24.35±5.19	12.14±4.34	14.71±3.20	8.90±2.99	60.11±12.06
p	0.820	0.238	0.427	0.133	0.378
Z	-.227	-1.181	-.794	-1.501	-.882
Marital status					
Married	23.74±5.68	12.85±4.20	14.89±3.32	9.53±3.07	61.03±12.74
Single	24.30±5.79	12.43±4.60	14.86±3.35	9.04±3.33	60.64±13.83
p	0.282	0.470	0.867	0.187	0.797
Z	-1.075	-.723	-.167	-1.319	-.257
Child					
No child	24.24±5.70	12.46±4.56	14.93±3.36	9.04±3.22	60.68±13.53
Child Yes	23.73±5.75	12.88±4.19	14.83±3.31	9.59±3.13	61.04±12.88
p	0.413	0.412	0.659	0.093	0.935
Z	-.819	-.821	-.659	-1.681	-.081
Profession					
Physician	24.88±3.60	11.81±4.39	13.40±3.02	8.51±2.47	58.62±8.48
Midwife	22.82±6.62	13.35±4.71	15.16±3.54	10.48±3.65	61.82±16.01
Nurse	24.15±5.67	12.62±4.27	14.99±3.28	9.15±3.07	60.91±12.87
p	0.540	0.274	0.015	0.005	0.212
KW	1.233	2.587	8.441	10.764	3.102
Education Status					
High School-Associate Degree	23.31±6.67	12.82±4.73	14.79±3.81	9.18±3.57	60.12±16.08
Undergraduate	24.29±5.17	12.66±4.09	14.99±3.07	9.44±2.96	61.38±11.43
Postgraduate	24.22±5.45	12.47±4.59	14.68±3.16	9.29±3.11	60.68±12.31
p	0.822	0.697	0.500	0.868	0.518
KW	0.392	0.722	1.387	0.282	1.316

Working Period					
5 years and below	24.10±5.60	12.79±4.40	14.96±3.33	8.92±3.25	60.77±12.84
6 years and above	23.88±5.82	12.60±4.35	14.82±3.33	9.62±3.10	60.95±13.43
p	0.958	0.655	0.673	0.027	0.690
Z	-.053	-.447	-.422	-2.208	-.398
Having a disabled relative					
Yes	24.70±4.50	12.64±4.36	15.44±2.88	9.54±3.14	62.33±11.67
No	23.67±6.14	12.70±4.38	14.64±3.47	9.25±3.20	60.27±13.73
p	0.548	0.982	0.087	0.602	0.651
Z	-.601	-.023	-1.713	-.522	-.651
Receiving training on caring for disabled people during education					
Yes	25.47±4.33	13.31±4.57	15.50±2.93	9.83±3.33	64.14±11.06
No	22.67±6.43	12.13±4.12	14.34±3.55	8.90±2.99	58.07±14.19
p	0.000	0.033	0.017	0.020	0.002
Z	-3.921	-2.133	-2.382	-2.331	-3.138
Receiving in-service training for caring for disabled people while working					
Yes	24.96±4.50	13.46±4.60	15.75±3.30	10.00±3.28	64.18±12.30
No	23.61±6.08	12.40±4.26	14.56±3.28	9.09±3.12	59.67±13.30
p	0.184	0.096	0.011	0.046	0.021
Z	-1.329	-1.664	-2.529	-1.994	-2.304
Communication with disabled individuals or receiving training that will facilitate caregiving					
Yes	25.63±5.09	14.00±4.75	15.93±3.52	10.23±3.829.24±3.10	65.80±14.81
No	23.79±5.77	12.54±4.31	14.76±3.29		60.34±12.90
p	0.071	0.095	0.029	0.134	0.032
Z	-1.807	-1.669	-2.187	-1.497	-2.139
Experience of caring for. Monitoring or treating disabled individuals					
Yes	24.89±4.81	13.06±4.25	15.30±3.01	9.68±3.12	62.93±11.39
No	22.26±6.83	11.98±4.52	14.10±3.74	8.69±3.20	57.03±13.17
p	0.002	0.059	0.023	0.015	0.009
Z	-3.129	-1.887	-2.281	-2.433	-2.614

X: Average, SD: Standard Deviation, Z: Mann Whitney U test, KW: Kruskal Wallis Test.

with disabled people and the disabled women and gender sub-dimensions and the DWAS total score, and between the status of having experience in caring for, monitoring or treating disabled individuals and the disabled women and their private lives, disabled women and social support, disabled women and gender sub-dimensions and the DWAS total score ($p \leq 0.05$) (Table 3).

Discussion

This study aimed to determine the attitudes of healthcare professionals towards disabled women, and also to reveal whether the attitudes of the participants differed in terms of some variables. In our study, the total DWAS score average of healthcare professionals was found to be 60.87 ± 13.17 (Min:17- Max:85). Considering that the lowest scale score was 17 and the highest scale score was 85, it can be said that the healthcare professionals participating in the study had a positive attitude towards disabled women. Similarly, Edis and Ketten reported in their study that healthcare professionals have positive attitudes towards disabled women (24). Unlike our study, a study conducted in Nepal revealed that healthcare professionals have negative attitudes towards disabled women and that their knowledge and skills regarding the care of these women are inadequate. In a study examining the attitudes of healthcare professionals towards disabled individuals, it was found that these attitudes are generally positive (18). Apaydın and Barış (2021) also reported that healthcare professionals have positive attitudes towards disabled individuals (17). In addition, another study conducted with physicians and nurses indicated that there is a moderately positive attitude towards disabled individuals (26). According to our study findings, although young participants have higher DWAS scores than older age groups, no significant relationship was found between age and DWAS score average ($p > 0.05$). Similarly, in the most comprehensive study conducted in our country to measure attitudes towards the disabled, it was reported that young people have more positive attitudes than older people (27). Similar results were found in another study conducted in our country (26).

In our study, although there was no significant difference between the gender of the participants

and the DWAS score average, it was observed that women had more positive attitudes than men. When the literature was examined, studies conducted showed that there was no difference in the attitudes of both genders towards the disabled (15,28). A study conducted in our country showed that there was a significant difference between the gender of healthcare professionals and the DWAS score averages and that the score averages of women were higher than those of men (24). Similar studies show that women have more positive attitudes towards disabled individuals than men (16,28,29). The reason why women have more positive attitudes towards disabled women may be due to the fact that they generally adopt a more sensitive and supportive approach towards disabled individuals due to factors such as empathy, social roles, personal experiences and awareness. In our study, no significant relationship was found between the marital status and number of children of the participants and the DWAS score average ($p > 0.05$). Similar to our study, Çıtlı and Kılıç (2019) also reported that the participants' status of marriage and having children did not have a significant effect on their attitudes towards disabled individuals (26).

In our study, no significant relationship was found between the participants' professions and the DWAS score average, and it was determined that midwives had a more positive attitude towards disabled women than nurses and doctors ($p > 0.05$). In a study conducted with healthcare professionals, it was determined that the profession did not affect attitudes towards disabled women. In addition, in the same study, it was determined that midwives and nurses had a more positive attitude towards disabled women than doctors and other healthcare professionals (24). It is thought that this situation is because the majority of nurses and midwives are women and therefore have better empathy with disabled women.

There was no significant relationship between the participants' education level and the DWAS score average ($p > 0.05$). The study conducted by Akça et al. (2024) with healthcare professionals also showed that there was no statistically significant difference between education level and attitudes towards disabled people (28). The literature is similar to our findings (24,26).

There was no significant relationship between the length of service of healthcare professionals and the DWAS score average ($p>0.05$). In another study, there was no statistically significant difference between the length of service and attitudes towards disabled women(24). Contrary to our study, there are also studies showing that there is a significant difference between the length of service and the attitude towards disabled individuals(26,28).

In our study, there was no significant relationship between the participants' status of having a disabled relative and the DWAS score average ($p>0.05$). However, the attitudes of disabled women were found to be higher in participants with disabled relatives than in those without disabled relatives. In the study by Edis and Keten (2024), it was found that healthcare professionals who have a disabled individual in their family have lower attitudes towards disabled women than those who do not(24). In addition, Kılıç and Çıtlı (2019) showed that nurses and doctors who have a disabled individual in their family have lower attitudes towards disabled individuals than those who do not(26). In a study conducted to determine the attitudes of healthcare professionals towards disabled individuals, it was stated that healthcare professionals who have a disabled individual in their family or close circle have lower attitudes towards disabled individuals than those who do not(18). Some studies show that interacting with disabled individuals positively affects attitudes towards these individuals(25,30). In our study, it was determined that participants who have a disabled relative have more positive attitudes towards disabled women than those who do not have a disabled relative. This situation reflects the effect of interaction with disabled individuals. In addition, a significant relationship was found between the status of having experienced care, monitoring, or treatment of disabled individuals and the DWAS score averages in our study ($p<0.05$). The mean DWAS scores of those who had experience in caring for, monitoring, or treating disabled individuals were found to be higher than those who did not have experience.

A notable finding in our study is that education is an important factor in the attitudes of healthcare professionals towards disabled women. In this

study, it was observed that there was a statistically significant difference between the average DWAS scores and the status of receiving training on the care of disabled individuals during education, receiving training on the care of disabled individuals while working, and receiving training to communicate with disabled individuals or to facilitate caregiving. Participants who received training on the care of disabled individuals during education, received in-service training on the care of disabled individuals while working, and received training to communicate with disabled individuals or to facilitate caregiving showed more positive attitudes towards disabled women. In the study conducted by Ayyıldız and Ulupınar (2019) with nurses working in primary care, it was reported that more than half of the nurses did not receive training on the disabled during their education(31). In the study conducted by Apaydın and Barış (2021) to determine the attitudes and awareness of healthcare professionals towards disabled individuals, it was determined that 73.4% of the participants did not receive any courses, seminars, or training on working with disabled individuals. In the same study, 80.4% of the participants reported that they wanted to receive training for disabled individuals(17). There are studies in the literature indicating that receiving previous training on disability has positive effects on attitudes towards disabled individuals(14,32,33). In the study by Geçkil et al. (2017), it was reported that empathy activities implemented to understand disabled individuals positively affected the attitudes of student nurses towards disabled individuals(34). In a study conducted in Istanbul, it was determined that 7 out of 10 healthcare professionals had difficulty communicating with disabled individuals and that the majority of healthcare professionals had not received any training on disabled individuals either before or in the institution where they worked(17). In the systematic review conducted by Evans et al. (2023) to investigate the effects of educational interventions on the attitudes and empathy levels of nursing and medical students towards disabled individuals, the effectiveness of the disabled health course, the disability education module with bedside training and the wheelchair workshop intervention was evaluated. At the end of the study, it was shown that the disabled health course, which uses the emotional learning

method based on transformative learning theory, significantly improves attitudes towards disability among nursing students(35). In this context, it is of great importance that education programs in the field of health increase awareness about providing respectful and equal services to individuals with disabilities. Pre-graduate and post-graduate education programs help healthcare professionals develop their attitudes by providing them with knowledge and skills on how to communicate and care for individuals with disabilities more effectively.

The attitudes of healthcare professionals towards women with disabilities are of great importance in providing healthcare services in a fair, equal and respectful manner. According to ethical principles, every individual has equal rights. However, women with disabilities have to struggle not only with physical disabilities but also with gender-based discrimination and social prejudices. This makes it difficult for them to access healthcare services and can result in a violation of their right to health(36-38). Healthcare professionals need to see women with disabilities as individuals, not only from a medical perspective but also from an ethical perspective, showing human respect. The insensitivity and prejudices in the approach of healthcare professionals to individuals with disabilities violate the principle of autonomy. Autonomy, one of the medical ethical principles, emphasizes the right of individuals to make their own healthcare decisions; however, women with disabilities may have difficulty exercising these rights due to the exclusionary attitudes of healthcare professionals towards them(39-41). Justice is one of the fundamental principles in health ethics. Women with disabilities are often excluded and ignored from society due to both their gender and their disability. This creates significant obstacles to their access to health services. Therefore, it is not only a professional responsibility but also an ethical obligation for health professionals to approach individuals with disabilities based on empathy and understanding. This approach will contribute to eliminating inequalities in health services(37,41,42). In addition, health professionals need to receive training on disability to prevent the violation of the rights of individuals with disabilities in social and health services(40,43). This

training increases the awareness of healthcare professionals, enables them to adopt a more ethical approach and ensures that women with disabilities can fully benefit from healthcare services. As a result, an ethically correct attitude in healthcare services will contribute to the achievement of social justice by ensuring that women with disabilities are treated based on equal rights, with respect and empathy.

Research limitations

This study is limited to midwives, nurses, and doctors working in secondary healthcare institutions in Adana, Turkey, and can only be generalized to this group. In addition, the fact that the study was conducted only in secondary health institutions, not all health personnel were included in the study, and the socio-economic, and educational level of the participants constitute the limitations of the study.

Conclusion

The attitudes of health workers towards women with disabilities are very important in ensuring that women with disabilities receive quality and qualified care from health services. The attitudes of health workers towards women with disabilities are directly related to basic ethical principles such as gender equality, accessibility and equal access to health services. Individuals with disabilities encounter various difficulties while benefiting from health services, and this situation can become even more complicated for women. The obstacles experienced by women with disabilities in accessing health services are shaped by both physical and social obstacles. In this context, the ethical evaluation of the attitudes of health workers towards women with disabilities plays an important role both in ensuring that professional health practices are compatible with human rights and in increasing the quality of health services. In this context, health personnel should exhibit a holistic approach in line with ethical principles in the care of women with disabilities and fulfill their professional responsibilities for all patients. In our study, the total mean score of DWAS used to determine the attitudes of healthcare professionals towards disabled women was found to be 60.87 ± 13.17 (Min:17-Max:85). Considering that the lowest

scale score was 17 and the highest scale score was 85, it can be said that healthcare professionals participating in the study had a positive attitude towards disabled women. It was determined that those who received in-service training on the care of disabled individuals during their education and while working, received training on communicating with disabled individuals or facilitating caregiving, and had experience in the care, monitoring, or treatment of disabled individuals, had a more positive attitude towards disabled women. It can be suggested that the education curricula of healthcare professionals be updated and supported with various teaching methods regarding the treatment and care of disabled individuals, and regular in-service training be provided in order to meet the educational needs of healthcare professionals. Finally, it is also suggested that qualitative research be conducted to examine the attitudes of healthcare professionals towards disabled women in more depth.

Competing interests

The author declare no competing interests.

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CULTURAL INFLUENCE IN FASHION MARKETING OF HEALTHCARE PRODUCTS: A CASE STUDY OF GB, PAKISTAN

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Abstract: This study examines the cultural factors influencing fashion tastes and marketing techniques of healthcare products in Gilgit-Baltistan (GB), Pakistan, emphasizing the region's distinctive amalgamation of tradition, traditional values, and contemporary influences. This research conducts a qualitative analysis of 120 theme responses from local participants to investigate the influence of cultural heritage, social norms, and technological advancements—specifically media and internet shopping—on fashion preferences and purchasing patterns of healthcare products. The findings underscore the pivotal influence of cultural identity and traditional values on fashion preferences, especially with modesty, community involvement, and local festivals. The study examines the increasing impact of social media and international fashion trends, as well as the obstacles and potential for local enterprises in incorporating cultural heritage into the fashion marketing of healthcare products. The study emphasizes the necessity of a balanced strategy that honors cultural traditions while integrating contemporary trends, offering insights for firms to effectively connect with local consumers. Ultimately, it proposes future study avenues centered on sustainability, digital transformation, and cross-cultural comparisons to further the comprehension of fashion marketing of healthcare products in culturally diverse areas such as Gilgit-Baltistan for healthcare products marketing.

Keywords: cultural heritage, fashion preferences, marketing strategies, modern influences, healthcare products

Influencia cultural en el marketing de moda de productos sanitarios: un estudio de caso de GB, Pakistán

Resumen: Este estudio examina los factores culturales que influyen en los gustos de moda y las técnicas de marketing de productos sanitarios en Gilgit-Baltistán (GB), Pakistán, destacando la distintiva fusión de tradición, valores tradicionales e influencias contemporáneas de la región. La investigación realiza un análisis cualitativo de 120 respuestas temáticas de participantes locales para investigar la influencia del patrimonio cultural, las normas sociales y los avances tecnológicos —específicamente, las compras en medios de comunicación e internet— en las preferencias de moda y los patrones de compra de productos sanitarios. Los hallazgos subrayan la influencia crucial de la identidad cultural y los valores tradicionales en las preferencias de moda, especialmente respecto de la modestia, la participación comunitaria y las festividades locales. Examina el creciente impacto de las redes sociales y las tendencias internacionales de moda, así como los obstáculos y el potencial de las empresas locales para incorporar el patrimonio cultural en el marketing de moda de productos sanitarios. Enfatiza la necesidad de una estrategia equilibrada que honre las tradiciones culturales, a la vez que integra las tendencias contemporáneas, ofreciendo perspectivas para que las empresas conecten eficazmente con los consumidores locales. Finalmente, propone futuras líneas de estudio centradas en la sostenibilidad, la transformación digital y las comparaciones interculturales, para profundizar en la comprensión del marketing de moda de productos sanitarios en zonas culturalmente diversas, como Gilgit-Baltistán.

Palabras clave: patrimonio cultural, preferencias de moda, estrategias de marketing, influencias modernas, productos sanitarios

Influência cultural no marketing de moda de produtos de cuidados à saúde: um estudo de caso em GB, Paquistão

Resumo: Esse estudo examina os fatores culturais que influenciam os gostos de moda e técnicas de marketing de produtos de cuidados à saúde em Gilgit-Baltistan (GB), Paquistão, enfatizando a singular fusão de tradição, valores tradicionais e influências contemporâneas daquela região. Essa pesquisa realiza uma análise qualitativa de 120 respostas temáticas de participantes locais para investigar a influência da herança cultural, normas sociais e avanços tecnológicos —especificamente compras pela mídia e internet— nas preferências de moda e padrões de compra de produtos de cuidados à saúde. Os achados destacam a influência crucial da identidade cultural e valores tradicionais nas preferências de moda, especialmente no que diz respeito à modéstia, ao envolvimento comunitário e aos festivais locais. O estudo examina os impactos crescentes da mídia social e tendências de moda internacional, bem como os obstáculos e potencial para empresas locais incorporarem herança cultural no marketing de moda de produtos de cuidados à saúde. O estudo enfatiza a necessidade de uma estratégia equilibrada que honre tradições culturais ao integrar tendências contemporâneas, oferecendo insights para empresas se conectarem com consumidores locais. Em última análise, propõe futuras linhas de estudos centradas em sustentabilidade, transformação digital e comparações interculturais para aprofundar a compreensão do marketing de moda de produtos de cuidados à saúde em áreas culturalmente diversas tais como o marketing de moda de produtos de cuidados à saúde em Gilgit-Baltistan.

Palavras chave: herança cultural, preferência de moda, estratégias de marketing, influências modernas, produtos de cuidados à saúde

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Introduction

The complex interplay between culture and consumer behavior is a vital element in the formulation of marketing strategies for fashion of healthcare products. In regions such as Gilgit-Baltistan (GB), Pakistan, where cultural legacy is profoundly embedded and unique, it is imperative to possess a comprehensive understanding of these influences. Gilgit-Baltistan is widely recognized for its diverse ethnic communities, rich traditions, and unique social dynamics. Cultural components significantly influence consumer decisions, purchasing behavior, and brand perceptions, offering a compelling context for exploring the convergence of culture and fashion marketing of healthcare products(1).

This study examines the cultural elements influencing the fashion marketing of healthcare products in Gilgit-Baltistan. This project aims to examine how local cultures, values, and social norms affect consumer choices in the fashion industry of healthcare products. This will be achieved through qualitative interviews with persons located throughout the region. This study elucidates the complexities of consumer behavior in a culturally diverse region, providing insights that businesses and marketers can leverage to develop tailored strategies that resonate with the local audience(2).

This research contributes to the broader discourse on cultural diversity in fashion marketing of healthcare products and underscores the importance of context-specific strategies in an increasingly globalized industry. This study aims to offer insightful perspectives for academics and industry professionals interested in the complex relationship between culture and commerce in the fashion industry of healthcare product marketing. This is achieved by concentrating on the unique cultural landscape of Gilgit-Baltistan(3).

In a progressively interconnected world, comprehending the cultural aspects of fashion marketing of healthcare products transcends geographical limits, providing significant insights into global consumer behavior. The interaction between tradition and modernity in Gilgit-Baltistan reflects analogous dynamics in other culturally affluent areas, where heritage-inspired fashion selections

coexist with global trends. This study enhances local market strategies and provides broader applicability for international brands aiming to operate in culturally sensitive countries. This research analyzes the influence of social conventions, digital media, and changing consumer preferences on fashion trends of healthcare products within a unique yet internationally pertinent context, offering a framework to guide marketing efforts across many cultural environments. These findings may be especially advantageous for international fashion firms of the healthcare product industry, legislators, and scholars seeking to reconcile cultural authenticity with market-driven adaptation in an age of swift globalization(4).

Background and Problem

A primary problem in the fashion marketing of healthcare products in Gilgit-Baltistan is the region's infrastructural deficiencies, which impede accessibility and the delivery of fashion products of healthcare products. The remote terrain and underdeveloped retail networks limit the availability of different fashion options, forcing many consumers to depend on online shopping, which, despite its growth, encounters logistical challenges such as inconsistent delivery services and restricted internet access in rural regions. Moreover, generational disparities significantly influence fashion inclinations. Younger generations are increasingly swayed by global fashion trends via social media and digital platforms, whilst older generations typically favor traditional apparel that reflects cultural history and modesty. The generational divide poses a marketing problem, requiring firms to mix innovation with heritage to attract a diverse consumer base. Comprehending these limits is crucial for enterprises seeking to formulate culturally adaptable and sustainable fashion marketing strategies for healthcare products that address the distinctive socio-economic and demographic context of Gilgit-Baltistan(5).

Novelty of Study

This study provides a distinctive contribution by concentrating on the culturally affluent yet academically under-researched area of Gilgit-Baltistan (GB), Pakistan. This study contrasts with prior research that mostly focuses on fashion marketing

of healthcare products in urban and globally interconnected markets by exploring how cultural history, societal norms, and contemporary influences affect consumer behavior in a geographically isolated and diversified context. This research offers new insights into the interplay of tradition and modernity in fashion marketing of healthcare products, considering the region's unique socio-cultural context, with significant implications for local enterprises and broader cross-cultural marketing tactics. This study addresses a research gap, enhancing comprehension of consumer preferences in GB and contributing to the conversation on culturally ingrained marketing strategies in emerging economies(6).

Research objectives:

The research objectives of this study are structured around understanding the dynamic interplay between cultural heritage and evolving fashion trends of healthcare products in Gilgit-Baltistan. Specifically, the study aims to explore how deeply rooted cultural values shape individual fashion preferences and the extent to which traditional attire reflects cultural identity in everyday life and special occasions(7). Furthermore, it aims to investigate the impact of social norms and community expectations on the adoption of diverse fashion trends and brands in the region for healthcare products. The study examines the influence of media and technology, namely social media platforms and online shopping, on fashion awareness and purchasing behaviors, evaluating whether these digital factors reinforce or contest local cultural norms. This research seeks to elucidate the significance of cultural heritage in fashion marketing of healthcare products strategies and examine how local enterprises can incorporate traditional elements into their campaigns to align more effectively with the preferences and expectations of the regional populace(8).

Research Questions:

Cultural Values and Fashion Preferences

How do the cultural traditions and values of Gilgit-Baltistan influence your choices in clothing and fashion of healthcare products? Can you share specific examples of how traditional or modern attire

reflects cultural identity in your daily life or on special occasions?

Impact of Social Norms on Fashion Trends

In your opinion, how do social norms and community expectations shape the adoption of fashion trends of healthcare products in Gilgit-Baltistan? Are there particular styles or brands that are more acceptable or admired within your community?

Role of Media and Technology in Fashion Awareness

How have media and technology, such as social media platforms and online shopping, affected the fashion preferences and purchasing behaviors of people in Gilgit-Baltistan for healthcare products? Do you think these platforms represent or challenge local cultural influences?

Business Perspectives on Cultural Integration in Marketing

For local businesses or marketers, what role does cultural heritage play in promoting fashion-related healthcare products in Gilgit-Baltistan? How can fashion marketing of healthcare product campaigns better align with the cultural values and expectations of the local population?

Literature Review

Cultural Influence in Fashion Marketing

Cultural influence has been recognized as a crucial factor in customer behavior, particularly in fashion marketing of healthcare products. Culture shapes individual choices, attitudes, and perceptions, acting as a crucial factor in the styles and trends that attract different people. Fashion, as a reflection of identity, serves as an expression of personality and a medium for expressing cultural narratives. Research demonstrates that cultural values, encompassing traditions, norms, and rituals, significantly influence the adoption of fashion trends, since consumers are often drawn to fashions that align with their social and cultural identities(9). The globalization of fashion has engendered new dynamics, leading to tensions between the preservation of cultural heritage and the embrace of modern global trends. This connection is particu-

larly evident in diverse and culturally rich regions, where traditional attire coexists with contemporary influences. The rise of digital platforms and media has intensified the relationship between culture and fashion, enabling the rapid dissemination of global trends while also offering opportunities for cultural preservation and localized marketing. The integration of cultural insights into fashion marketing strategies for healthcare products, while significant, is inconsistent, highlighting the need for research that links cultural understanding with business realities. This analysis provides a basis for investigating the impact of cultural factors on fashion marketing techniques for healthcare products, focusing on the unique and under-explored area of Gilgit-Baltistan, Pakistan(1,10).

Cultural Values and Their Impact on Fashion Preferences

Cultural values serve as a foundational guide for individual and collective behaviors, significantly influencing preferences in fashion and attire. Theoretical theories, such as Hofstede's cultural dimensions, provide valuable insights into how individualism, collectivism, and power distance affect fashion tastes in various countries. Cultural hegemony and symbolic interactionism similarly highlight the power dynamics and social meanings embedded in clothing, illustrating how fashion serves as both a reflection and reinforcement of society's standards. Traditional and heritage-based garments often represent cultural identity, symbolizing values, history, and a connection to one's roots(11,12).

In regions like Gilgit-Baltistan, clothing selections are rooted in cultural traditions that embody unique ethnic and religious identities. Traditional attire functions as a manifestation of aesthetic choices and a marker of communal affiliation and social status. However, the influence of current trends and globalized fashion has started to alter these preferences, leading to a blend of traditional and modern styles. Case studies from similar culturally affluent regions demonstrate the considerable impact of cultural identification on consumer choices, as individuals often select clothes that embody their values while aligning with current trends(13). Comprehending these factors is essential for fashion marketers seeking to create and

promote products that appeal to culturally varied customers. This section analyses the complex relationship between cultural values and fashion preferences, establishing a basis for investigating how these notions are expressed in Gilgit-Baltistan(14).

Social Norms and Their Role in Fashion Adoption

Social norms profoundly impact fashion adoption, acting as implicit criteria that dictate acceptable behaviors and choices within a community. Social acceptance significantly impacts consumer behavior, as individuals often conform to collective preferences to get favor and maintain their social identity. Community expectations shape fashion trends by fostering ideas of suitability or appeal within a specific cultural or social framework. Such expectations can affect the prevalence of particular styles, often cultivating a sense of belonging among its followers(15,16).

Gender-specific standards complicate matters, as societal norms surrounding masculinity and femininity often dictate suitable attire for men and women. In older communities, norms may restrict fashion choices to culturally acceptable attire, while in more contemporary settings, they may evolve to encompass diverse and unorthodox styles. The interplay between social norms and fashion highlights the imperative for marketers to consider the cultural and social context of their target audience when formulating campaigns or promoting trends. This review analyzes the effect of these dynamics on fashion adoption, offering insights into the impact of cultural norms on consumer behavior in regions such as Gilgit-Baltistan(17,18).

Media and Technology as Drivers of Fashion Awareness

The swift advancement of media and technology has transformed fashion marketing, altering customer interaction with trends and businesses. Digital media has emerged as a pivotal force in fashion awareness, enabling marketers to engage varied audiences via visually engaging and interactive platforms(19). Social media has become a

potent instrument in changing cultural conceptions of fashion, as influencers, content providers, and brands construct trends that appeal to both global and local audiences. These platforms promote immediacy and connectedness, facilitating the spread of trends across cultural boundaries while enabling individuals to express their distinct cultural identities(20).

The amalgamation of e-commerce and digital marketing in culturally diverse areas such as Gilgit-Baltistan presents both challenges and prospects. While internet platforms offer unmatched access to global fashion, they must also account for the unique cultural preferences and sensitivities of the local population. Aligning marketing techniques with local values and practices enhances client trust and engagement(21). Conversely, barriers such as a lack of digital literacy and insufficient infrastructure in rural areas may hinder the adoption of e-commerce solutions. This section critically examines the dual role of media and technology as facilitators of global fashion awareness and as instruments for preserving and promoting local cultural influences in fashion marketing of health-care products(22).

Fashion Marketing in the Context of Local Cultures

Fashion marketing thrives at the intersection of cultural heritage and modern innovation, requiring companies to skillfully navigate the complexities of integrating cultural motifs into their branding strategy. Incorporating local cultural themes, practices, and values into fashion branding allows companies to forge authentic connections with their target audience, fostering loyalty and community involvement. Effective strategies often involve collaboration with local artisans, the use of culturally pertinent patterns or motifs, and tales that highlight the cultural legacy of products(23).

Reconciling traditional values with global changes is a distinct difficulty. Although globalisation has exposed consumers to modern fashion trends, a substantial segment of the population remains firmly anchored in their cultural identities, necessitating marketers to achieve a nuanced equilibrium. This equilibrium can be attained by tailoring global designs to local tastes or endorsing

hybrid forms that amalgamate heritage and modernity(24).

The Unique Cultural Landscape of Gilgit-Baltistan

Gilgit-Baltistan, situated in the northernmost region of Pakistan, exhibits a rich diversity of cultures and ethnicities. The region is home to various ethnic groups, including the Shina, Balti, Wakhi, and Burusho, whose cultural identities are shaped by a blend of languages, traditions, and historical influences. Diversity is seen in traditional attire, which acts as a crucial indicator of heritage, communal identity, and social status. Distinctive clothing styles, such as Balti woolen robes, Shina embroidered headgear, and vibrant Wakhi gowns, represent the region's cultural richness and are functionally suited to its harsh weather circumstances(25).

Nonetheless, the fashion inclinations of Gilgit-Baltistan's populace are transforming due to globalisation, more connections, and exposure to contemporary styles. Younger generations are integrating traditional components with current fashions, producing a distinctive synthesis that embodies cultural pride and modern aspirations. Notwithstanding these alterations, traditional costume continues to be a fundamental aspect of special events, festivals, and communal gatherings, highlighting its lasting significance(26).

Consumer Behavior and the Role of Local Businesses in Fashion Marketing

Cultural factors markedly impact consumer choices in Gilgit-Baltistan, where traditions, morals, and regional aesthetics deeply shape fashion preferences. Religious convictions, familial influences, and community dynamics are essential in purchasing decisions, since they often dictate the appropriateness of trends and the importance of modesty in apparel. Moreover, significant discrepancies exist between urban and rural consumers. Urban areas generally embrace modern trends and brand identity, whilst rural villages remain rooted in traditional attire, reflecting their cultural heritage(27).

Bridging Cultural Heritage and Modern Marketing Strategies

Effectively integrating cultural heritage with contemporary marketing necessitates cooperation between marketers and communities. Co-creation, which incorporates local voices and traditions into product design and marketing strategies, guarantees authenticity and enhances consumer trust. This strategy enables marketers to develop products that align with cultural values while satisfying modern requirements(28).

Narrative is an influential instrument in culturally anchored marketing initiatives. By elucidating the origins, meaning, and workmanship of traditional clothes, marketers may cultivate emotional ties with consumers, thereby enhancing loyalty and pride in local history. Nevertheless, innovation must be judiciously harmonised with cultural sensitivity. Marketers must honour cultural conventions and values while integrating contemporary features, ensuring that new designs or campaigns do not estrange or insult their target. This deliberate amalgamation of culture and innovation facilitates significant and effective marketing techniques(29).

Synthesis of Literature and Gaps

Recent research highlights the substantial influence of culture on fashion marketing, demonstrating how traditions, social norms, and collective values affect consumer behavior and brand strategy. Research demonstrates that incorporating cultural elements into fashion branding enhances authenticity and fosters more robust consumer interactions. Theoretical frameworks such as Hofstede's cultural dimensions and symbolic interactionism have been extensively employed to clarify the connection between cultural identity and fashion choices. Similarly, studies on social media and e-commerce underscore the growing importance of technology in promoting both global trends and localized fashion narratives. Case studies from many nations illustrate the effectiveness of culturally sensitive marketing strategies in enhancing client loyalty and preserving heritage(30).

This study seeks to fill these gaps by offering a detailed comprehension of fashion marketing of

healthcare products within the cultural dynamics of Gilgit-Baltistan. The research provides significant insights for marketers and policymakers by examining consumer behaviour, the function of local businesses, and the amalgamation of legacy with contemporary trends. It also enhances broader discussions on the preservation of cultural identities while promoting innovation in marketing techniques, rendering it an essential contribution to the current body of knowledge(31).

Digitalization and Fashion Marketing

The emergence of digitization has significantly transformed the realm of fashion marketing, affecting customer interaction and brand tactics. Digital platforms, including social media, e-commerce sites, and virtual storefronts, have allowed fashion firms to access broader audiences while offering tailored purchasing experiences. In culturally rich and emerging areas such as Gilgit-Baltistan, where conventional retail infrastructure may be inadequate, digitization has alleviated accessibility disparities by linking local consumers to global fashion trends. Social media influencers, targeted advertising, and algorithmic content curation have profoundly influenced purchasing behaviors, affecting consumer exposure to contemporary and classic fashion styles. The transition to digital commerce has enabled local craftspeople and small-scale fashion enterprises to present culturally significant designs to both national and international markets, promoting economic development while safeguarding history. Nonetheless, digital literacy, internet accessibility, and logistical obstacles persist as significant impediments in the region, affecting the efficacy of digital marketing techniques in reaching varied consumer demographics(32).

The Role of E-Commerce and AI in Fashion Market Expansion

E-commerce platforms, enhanced by breakthroughs in artificial intelligence (AI) and big data analytics, have transformed the fashion marketing of healthcare products through hyper-personalized recommendations and predictive trend research. AI-generated insights allow organizations to customize marketing communications, refine product selections, and improve consumer en-

gements based on behavioral trends. In areas such as Gilgit-Baltistan, where fashion choices are profoundly influenced by cultural traditions, AI-driven recommendation systems can harmonize local aesthetics with emerging global trends, offering tailored ideas that align with consumer values. Moreover, augmented reality (AR) and virtual try-on technologies are revolutionizing the internet shopping experience by alleviating consumer apprehensions regarding fit and style, hence decreasing return rates(33). The incorporation of these technologies in digital fashion marketing of healthcare products not only bolsters customer confidence in online transactions but also enables local firms to distinguish themselves by providing immersive experiences that emphasize the cultural importance of their designs. The use of these advanced digital technologies relies on enhancements in infrastructure and the bolstering of consumer confidence in digital transactions, both of which necessitate strategic development to fully realize the promise of digitalized fashion marketing of healthcare products in the region(34).

Fashion marketing in healthcare products

In the context of Gilgit-Baltistan, cultural identity plays a decisive role in shaping the fashion marketing of healthcare products, where traditional aesthetics are deeply intertwined with social values such as modesty, familial approval, and community representation. Unlike metropolitan markets, where fashion trends may evolve rapidly and are often driven by individual expression, GB consumers tend to make choices influenced by collective cultural frameworks and regional festivals that reaffirm heritage. Local fashion marketing of healthcare products—ranging from health-supportive garments like thermal wear and culturally styled facemasks to functional yet modest apparel—is increasingly reflecting this intersection of tradition and modernity. Research suggests that integrating indigenous design elements and local storytelling into branding strategies not only elevates consumer engagement but also fosters a sense of cultural preservation in the face of globalization. Thus, effective fashion marketing in healthcare contexts must transcend aesthetics and align with the symbolic and ethical codes of the community, reinforcing the idea that cultural congruence is not a constraint but a strategic advantage

in regional markets such as Gilgit-Baltistan.

Methodology

This study utilises a qualitative research approach to examine the cultural impact on fashion marketing of healthcare products in the diversified and culturally affluent region of Gilgit-Baltistan (GB), Pakistan. The approach was meticulously designed to guarantee depth, authenticity, and rigour, conforming to recognised qualitative research criteria(35).

Plan for the Research

Because of its ability to capture the diverse opinions, experiences, and cultural dynamics that influence consumer behaviour and marketing strategies in GB, the qualitative approach was selected as the method of investigation. It is very useful for comprehending complicated social phenomena, where context and cultural complexities play a significant role, and qualitative research is particularly helpful in this regard(36).

A Selection of Samples

In order to pick thirty respondents from a variety of districts in Gilgit-Baltistan, the research project made use of a technique known as purposive sampling. By using this strategy, we were able to ensure that the sample comprised a varied representation of society. This included participants from a variety of age groups, occupations, ethnic groupings, and socio-economic backgrounds. Those respondents who had firsthand knowledge or insight into fashion preferences, cultural norms, and consumer behaviour in the region were the focus of the inclusion criteria(37).

Collecting Numbers

A series of semi-structured in-depth interviews that were semi-structured was used to acquire the data. This structure allows us flexibility in examining the distinct viewpoints of respondents while providing uniformity across important theme areas. In order to promote a rich understanding of the cultural, social, and economic aspects that influence fashion marketing of healthcare products in GB, open-ended questions were used to stimulate thorough replies from survey partici-

pants. The accessibility of respondents was taken into consideration when determining whether interviews were performed in person or through virtual platforms(38).

Study of the Data

The data that were obtained were transcribed and then analysed using theme analysis, which is a method that is widely recognised in qualitative research. Steps such as the following were included in the process:

1. Familiarisation: To get a comprehensive comprehension of the material, the transcriptions were examined on many occasions.

During the coding process, essential phrases, ideas, and concepts were recognised and subsequently converted into codes. We used an inductive approach to construct the codes, which ensured that they arose directly from the data.

3. Classification: Codes that were related to one another were categorised into more general categories and themes.

4. Interpretation: To get insights and comprehend patterns within the data, themes were analysed and interpretations were made.

Throughout the entirety of the research procedure, ethical rules were adhered to in a stringent manner. Through the process of obtaining informed permission from each participant, it was ensured that they were aware of the objectives of the study, the processes involved, and their right to withdraw from the study at any time. All personal identifiers were removed from the data, ensuring that the respondents' anonymity and confidentiality were preserved.

Validity and dependability are both important.

For the purpose of enhancing the validity and reliability of the study, the following strategies were successfully implemented:

- Triangulation: using the purpose of ensuring consistency, the data were cross-verified using the insights of a variety of respondents.

- Member Checking: To ensure that the interpretations of their interviews were accurate, respondents had the opportunity to check them.

- Detailed Description: Accounts of the setting, participants, and conclusions were provided in great detail to enable readers to evaluate the transferability of the study.

When conducting qualitative research in areas with a complex cultural landscape, it is essential to choose approaches that are relevant to the context. The usefulness of purposive sampling for its ability to capture cultural variety and thematic analysis for its ability to extract relevant insights from rich, unstructured data is highlighted by studies conducted in situations that are comparable to those described above. For instance, studies that investigate consumer behaviour in rural and indigenous communities frequently emphasise the relevance of semi-structured interviews, which enable participants to freely interpret their experiences. In addition, the incorporation of cultural viewpoints into the study helps to increase the relevance and applicability of the findings in situations like these.

The approach that was selected is in accordance with the aims of the study since it offers a comprehensive comprehension of the dynamic relationship that exists between cultural heritage and fashion marketing of healthcare products in GB. The study provides nuanced insights into the intricacies of consumer behaviour, the obstacles faced by local businesses, and the prospects for culturally sensitive marketing tactics. These insights are made possible by the study's concentration on qualitative approaches. The results of this study not only fill in the gaps that have been identified in previous research, but they also provide a significant contribution to the field of cultural studies and fashion marketing of healthcare products in general.

Enhancing Data Validation and Thematic Analysis Rigour

To further enhance the rigour of the research process, additional measures were implemented to strengthen data validation and thematic analysis. Thematic analysis followed a structured, multi-stage approach to ensure credibility and consis-

tency. After initial coding, a second round of review was conducted, where codes were reassessed and refined to eliminate redundancy and improve coherence. To validate the emergent themes, peer debriefing sessions were held with qualitative research experts, allowing for external verification of the interpretations. Additionally, inter-coder reliability was established by involving an independent researcher who reviewed a subset of the data to confirm the consistency of the coding framework. This iterative process ensured that themes accurately reflected the underlying patterns in the data, enhancing the trustworthiness of the findings. Furthermore, respondent validation was incorporated, where participants were invited to review preliminary interpretations, ensuring that their perspectives were authentically represented. These rigorous validation techniques reinforce the credibility and reliability of the thematic analysis, thereby strengthening the overall methodological robustness of the study(39).

Data Analysis and Results

The procedures for qualitative data analysis were utilised in order to examine the information that was gathered from the thirty in-depth interviews. The purpose of this study was to provide a comprehensive understanding of the cultural effects on fashion marketing of healthcare products in Gilgit-Baltistan by carefully examining each response and identifying themes and trends. It was decided to produce tables of frequencies to quantify the extent to which particular themes and categories were present throughout the data. It was also decided to construct cumulative results in order to show the overall trends and insights that were provided by the respondents. The analysis made certain that each issue was treated methodically, and that the responses from all thirty participants were taken into consideration in order to arrive at results that were significant(40).

Cultural Values and Fashion Preferences⁵

The analysis of the data, guided by the research question in Table 2, highlights how cultural traditions and values in Gilgit-Baltistan significantly influence clothing and fashion preferences. Tradition and Cultural Identity emerged as the most

dominant themes, each accounting for 23% of responses. These findings underscore the deep-rooted importance of ancestral heritage, family traditions, and pride in cultural identity, which manifest through choices in traditional attire for daily life and special occasions. Modesty (13%) reflects the alignment of fashion with religious and moral values, emphasizing decency and respect. Similarly, Festivals (13%) highlight the role of cultural celebrations, such as weddings and local events, in sustaining traditional fashion practices. Community and Influence, each contributing 10%, showcase the interplay between societal expectations, community values, and modern fashion trends, reflecting a blend of tradition and contemporary influences. Lastly, Work and Daily Attire (7%) illustrates practical considerations, emphasizing comfort and utility in everyday clothing. Overall, the findings demonstrate that fashion in Gilgit-Baltistan is deeply intertwined with cultural values, traditions, and evolving social norms, balancing heritage with modern trends to reflect cultural identity.

Impact of Social Norms on Fashion Trends

The analysis of the thematic main keywords in Table 4 and their classification reveals critical insights into the impact of social norms and community expectations on the adoption of fashion trends in Gilgit-Baltistan. Among the eight identified themes, Modesty emerged as the most prominent, with a frequency of 16.67%, reflecting the significant influence of religious standards, women's modesty, and conservative designs on fashion choices in the region. This highlights how deeply entrenched cultural and religious norms shape preferences, ensuring that clothing aligns with societal expectations of decency and respectability.

Themes such as Cultural Values, Blended Designs, Social Influence, Tradition and Heritage, and Practicality each contributed equally, with frequencies of 13.33%. This demonstrates a balance between adherence to traditional values, the growing acceptance of modern fashion blended with cultural elements, and the practical considerations that inform daily attire and fashion choices. Social influence, driven by peer interactions, social gatherings, and the impact of platforms like social media, underscores the community's role in

⁵ Todas las tablas se publican luego de las referencias.

setting and propagating fashion trends. Similarly, tradition and heritage emphasize the continuity of cultural events and elder guidance in preserving regional fashion identity.

Individuality and Local Preferences, with frequencies of 10% and 6.67%, respectively, reflect a smaller yet significant segment of respondents who prioritize personal expression and localized tastes in fashion. These themes illustrate a nuanced landscape where individuality is increasingly valued amidst collective cultural influences.

Overall, the findings highlight a complex interplay of tradition, social norms, and modernity in shaping fashion trends in Gilgit-Baltistan. The region's unique cultural dynamics ensure that fashion choices remain rooted in its rich heritage while gradually embracing global influences, showcasing a blend of continuity and change driven by community expectations.

Role of Media and Technology in Fashion Awareness

The analysis of the 30 interview responses in Table 6 highlights how media and technology influence fashion preferences and purchasing behaviors in Gilgit-Baltistan, revealing a complex interplay of social norms, cultural values, and modern trends. Social Media Influence emerged as the most prominent theme, accounting for 16.67% of the responses, with key factors such as influencers, celebrity trends, global fashion exposure, and peer sharing shaping consumer decisions. Modern Fashion Trends also held significant weight at 16.67%, with respondents emphasizing the role of modern designs, style updates, and the integration of Western and fusion styles.

Cultural Identity was another important factor, contributing 13.33% of responses, as participants highlighted the tension between cultural pride and local representation versus the global trends promoted by media platforms. Practicality, also at 13.33%, reflected the importance of convenience, accessibility, and rural access in shaping purchasing behaviors, particularly through online shopping.

Themes such as Value-Based Challenges (10%)

and Economic Influence (10%) underscore how fast fashion, price comparisons, and international brands both support and challenge local norms and affordability concerns. While Local and Traditional Brands and Innovation and Experimentation each accounted for 6.67%, they revealed opportunities for preserving cultural traditions through local craftsmanship and customizing modern trends to fit regional preferences.

Overall, the findings underscore the dual role of media and technology as both a driver of modern fashion awareness and a challenge to cultural traditions. Social media, online shopping, and technological advancements have expanded fashion accessibility while introducing influences that sometimes conflict with regional cultural norms. This tension underscores the need for balanced strategies to integrate modernity with cultural preservation, ensuring inclusivity and respect for local identities.

Business Perspectives on Cultural Integration in Marketing

The analysis of responses to the question on cultural integration in fashion marketing of healthcare products in Gilgit-Baltistan reveals six key themes as shown in Table 8. The most significant theme, Cultural Heritage, accounts for 20.00% of the responses, emphasizing the importance of traditional designs, ancestral themes, and cultural sensitivities in aligning fashion campaigns with local expectations. Following closely, Community and Local Involvement and Cultural Pride and Identity each account for 16.67% of the responses. These themes highlight the value of engaging local artisans, fostering community input, and showcasing regional pride and generational balance to resonate with the target audience. Similarly, Marketing Approaches (16.67%) stresses storytelling, visual communication, and cultural education as tools for emotionally connecting with consumers. Ethical and sustainable practices, encompassing modesty and cultural authenticity, also make up 16.67% of the responses, reflecting a growing preference for socially responsible fashion. Lastly, Festivals and Traditions (13.33%) underscore the role of cultural events and traditional patterns in creating timely and meaningful marketing opportunities. Collectively, these findings demonstrate

that integrating cultural heritage, fostering local pride, and maintaining ethical integrity are vital for crafting effective and culturally resonant fashion marketing of healthcare product marketing strategies in Gilgit-Baltistan.

Over all results for influencing factors

The analysis in Table 9 reveals that cultural heritage is the cornerstone of fashion marketing of healthcare products in Gilgit-Baltistan (GB), reflecting the region's deep-rooted traditions and historical identity. A significant proportion of responses emphasize the importance of aligning marketing campaigns with traditional values, ancestral themes, and authentic cultural expressions. This highlights the need for businesses to create strategies that resonate with the local population's pride in their heritage, using storytelling and culturally relevant motifs to forge strong connections.

Modern influences are another critical factor shaping fashion preferences in GB. Social media platforms, online shopping, and exposure to global trends have introduced contemporary aesthetics into the local market. However, this influence does not negate cultural traditions but instead fosters a blending of modern and traditional styles. Consumers are increasingly drawn to fashion that balances modernity with cultural significance, suggesting that businesses should integrate global trends with local motifs in their offerings.

Community and identity also play a pivotal role in shaping fashion marketing of healthcare products in the region. Responses underline the collective nature of fashion preferences, with community alignment, local involvement, and social influences acting as key drivers. Campaigns that foster inclusivity, promote local pride, and celebrate community values are likely to find strong acceptance among consumers.

Practicality and events emerge as influential factors, as traditional attire often serves both functional and cultural purposes. Festivals and local traditions significantly shape consumer behavior, with seasonal and event-specific designs being particularly valued. Marketing strategies that incorporate practical and culturally relevant designs for special occasions can effectively tap into this

segment of the market.

Ethics and modesty are deeply embedded in GB's fashion culture, reflecting the conservative values of the region. Ethical practices such as sustainability, modest design principles, and cultural sensitivity are critical for gaining consumer trust. Businesses that prioritize these aspects can build long-term loyalty and enhance their reputation in the local market.

Economic considerations also influence fashion preferences in GB, with affordability, accessibility, and support for local craftsmanship being crucial. Consumers appreciate brands that offer value while promoting local artisans and products. Additionally, the increasing role of online shopping and customization indicates a shift toward more innovative and convenient purchasing behaviors.

Discussions of Results

The findings of this study underscore the profound impact of cultural heritage and social norms on fashion preferences in Gilgit-Baltistan (GB). Cultural heritage emerged as a cornerstone, shaping both individual and collective fashion choices. The alignment of fashion with traditional values, ancestral themes, and cultural authenticity highlights the population's pride in preserving their identity. This cultural consciousness drives preferences for traditional attire, particularly during special occasions such as festivals and weddings, serving as a visible expression of regional identity. The interplay between tradition and modernity, evidenced by the popularity of blended designs and modern fashion trends, suggests a nuanced acceptance of global influences while maintaining cultural authenticity. Businesses operating in this region must navigate this balance by integrating local motifs with contemporary aesthetics to appeal to both traditional and modern consumer sensibilities.

Modern influences, particularly through media and technology, play a pivotal role in shaping fashion awareness and purchasing behavior in GB. Social media platforms and online shopping have introduced global trends, creating a dual dynamic of modernity and cultural pride. While these platforms challenge traditional norms by introducing

Western styles, they also provide opportunities for promoting local traditions and craftsmanship. The tension between cultural preservation and the adoption of global trends highlights the need for culturally sensitive marketing strategies. For instance, campaigns that use storytelling or emphasize cultural motifs while leveraging digital platforms could bridge the gap between local traditions and contemporary demands, ensuring that fashion remains relevant and accessible to the younger, tech-savvy demographic.

The analysis also revealed the influence of community, ethics, and practicality on fashion trends in GB. Community expectations and social norms significantly shape preferences, with societal approval being a key determinant of acceptable styles. Ethical considerations, such as modesty and sustainability, reflect the region's deeply rooted values and religious principles. The growing importance of practicality, especially in daily attire, and economic factors like affordability and support for local artisans further emphasize the importance of tailoring fashion strategies to local needs. These findings collectively suggest that businesses must adopt a holistic approach, incorporating cultural heritage, ethical practices, and economic accessibility, to create fashion offerings that resonate with GB's diverse and evolving population.

Bridging Tradition and Modernity in Fashion Choices

The findings further reveal that the tension between modernity and tradition is not a rigid divide but a fluid negotiation influenced by generational differences, economic factors, and exposure to global trends. Younger consumers in GB, while valuing their cultural roots, are more inclined to experiment with contemporary styles, often blending traditional elements with modern silhouettes to create hybrid fashion expressions. This adaptation signifies an evolving cultural identity rather than a rejection of tradition. On the other hand, older generations and conservative segments of society advocate for the preservation of authentic attire, viewing external influences as a potential dilution of cultural heritage. This generational contrast indicates a shifting yet coexisting fashion landscape where businesses must strategically position themselves to cater to both audiences. By offering cus-

tomizable designs that allow consumers to incorporate traditional embroidery, patterns, or fabric choices into modern outfits, businesses can bridge the gap between cultural preservation and evolving fashion preferences, ensuring that tradition remains relevant within modern consumer lifestyles.

Theoretical Contribution Enhancement

This study contributes to cross-cultural marketing theory by highlighting how cultural heritage, social norms, and modern influences interact to shape consumer behavior in a unique, culturally rich region like Gilgit-Baltistan. The findings align with the principles of cross-cultural marketing, emphasizing the need for localized branding strategies that integrate traditional values with global trends. By demonstrating how fashion choices are influenced by both deep-rooted cultural identity and exposure to modernity, this study extends theoretical discussions on cultural adaptation in consumer markets, offering insights applicable to other regions experiencing similar cultural transitions.

Conclusion

This study provides a comprehensive understanding of how cultural influences shape fashion preferences and marketing strategies of health care products in Gilgit-Baltistan (GB), highlighting the interplay between tradition, modernity, community, and ethics. Cultural heritage emerges as a dominant factor, with traditional attire and ancestral themes playing a pivotal role in defining fashion choices and reflecting the region's identity. The importance of cultural values underscores the need for businesses to respect and integrate local traditions into their marketing and product design to ensure authenticity and acceptance.

Modern influences, driven by social media and online platforms, reveal a gradual shift towards blending traditional motifs with contemporary aesthetics. This fusion offers opportunities for innovation while maintaining cultural relevance. The growing awareness of global trends does not displace local traditions; rather, it fosters an adaptive and dynamic approach to fashion that integrates the best of both worlds.

Community expectations, ethical considerations, and practical needs further shape the landscape of fashion in GB. Modesty and sustainability are highly valued, reflecting the region's moral and cultural framework. Practicality and affordability also play significant roles in daily fashion choices, indicating the importance of function alongside cultural and aesthetic appeal. Businesses aiming to succeed in this region must adopt a multidimensional strategy that respects cultural values, leverages modern technology, and addresses the economic realities of the local population.

From an academic perspective, this research contributes to the broader discourse on cross-cultural marketing by demonstrating how deeply ingrained cultural traditions influence consumer behavior in emerging markets. It reinforces the importance of culturally adaptive marketing frameworks that balance traditional and contemporary influences. Practically, the findings offer actionable insights for businesses, policymakers, and fashion marketers aiming to develop strategies that resonate with culturally diverse consumer bases. By bridging theoretical understanding with real-world applications, this study provides a foundation for future research on fashion marketing of healthcare products in culturally rich but underexplored regions like GB.

Future research direction and limitation

Future research could extend this study to other regions with similar cultural characteristics to explore the broader applicability of the findings. A comparative analysis between Gilgit-Baltistan and other culturally rich regions would provide deeper insights into the interplay between tradition and modernity in fashion marketing. Additionally, incorporating a quantitative approach, such as surveys or statistical modeling, could complement the qualitative findings by providing empirical validation and measuring the extent of cultural influences on fashion preferences and consumer behavior.

Despite the study's comprehensive approach, certain limitations must be acknowledged. The sample, though diverse, may not fully capture the entire spectrum of fashion preferences across all socio-economic and ethnic groups in Gilgit-Baltistan. Additionally, the reliance on qualitative data, while valuable for in-depth insights, limits the generalizability of findings to broader populations. Future research could incorporate larger and more diverse participant pools, as well as mixed-method approaches, to enhance the robustness and applicability of the results.

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Table 1 Responses for Q N° 1

Respondent	Response	Keyword
1	Our traditional attire, like the woolen shawl, is something I wear for special events. It connects me to our cultural roots.	Traditional
2	For weddings, I wear the Balti dress to represent my culture. It reflects my identity.	Cultural identity
3	I prefer wearing traditional garments like the Shalwar Kameez, as it is a symbol of respect for our traditions.	Tradition
4	On Eid, I wear a local dress that my grandmother wore, keeping the family tradition alive.	Heritage
5	My clothing choices for festivals are always traditional. The colors and styles are important in showing our cultural values.	Festivals
6	I wear modern clothing for work, but for community events, I always wear traditional attire to honor our heritage.	Modern vs. Traditional
7	Our traditional attire, like the embroidered cap, gives me a sense of belonging to my community.	Community
8	During religious ceremonies, I wear modest traditional clothing to show respect to our customs.	Modesty
9	In my daily life, I wear traditional clothes, as they are comfortable and connect me to my family.	Comfort
10	When attending a wedding, I wear a traditional woolen gown. It's a symbol of respect and a way to honor our history.	Respect
11	I always wear a traditional dress on religious occasions to connect with the values of our culture.	Religious values
12	For work, I wear modern clothing, but on holidays, I wear traditional attire to showcase my cultural pride.	Pride
13	My family insists on wearing traditional clothing during festivals, as it's a way of keeping our heritage alive.	Family tradition
14	On special occasions, I wear local fabric dresses because they carry the stories of our ancestors.	Ancestors
15	I like to combine traditional patterns with modern clothing for a unique style that reflects both worlds.	Fusion
16	For me, wearing traditional clothes on Eid is a way of feeling connected to my roots and culture.	Connection
17	Modern fashion trends influence me, but I try to make sure my clothing always reflects my cultural values.	Cultural influence
18	During family gatherings, I wear traditional attire as it shows the respect we have for our ancestors.	Family respect
19	I dress traditionally on religious days to honor our beliefs and to feel connected with my community.	Beliefs
20	I wear modern fashion for work, but when it comes to cultural events, I always choose traditional attire.	Work attire
21	Our culture emphasizes modesty, so I always choose clothing that aligns with those values.	Modesty
22	I enjoy wearing traditional dresses on festivals because they make me feel proud of my heritage.	Pride
23	When attending a wedding, I wear a traditional outfit as it represents my cultural identity.	Wedding
24	I always wear locally made clothes during festivals, as it supports local artisans and reflects our culture.	Local artisans
25	For me, traditional clothing on special occasions is about honoring my ancestors and their way of life.	Ancestral honor
26	Although modern fashion influences me, I never forget to wear cultural attire during important cultural celebrations.	Influence
27	On major religious holidays, I wear traditional attire to preserve the cultural values passed down by my family.	Religious traditions
28	I wear modern clothes day-to-day, but for family events, I prefer traditional dresses to feel connected to our history.	History
29	Our community values traditional attire for special occasions, so I always wear it to maintain that connection.	Community values
30	I wear modern clothing at work, but on cultural days, I always wear traditional attire to honor our customs.	Honor customs

Table 2 Thematic Words classification for Question N° 1

Serial Number	Thematic Main Key Word	Classified Key Words	Respondent Numbers	Frequency	%
1	Tradition	Traditional, Tradition, Heritage, Modern vs. Traditional, Family tradition, Ancestral honor, Religious traditions	1,3,4, 6,13, 25, 27	7	23%
2	Cultural Identity	Cultural identity, Connection, Pride, Respect, Pride, History, Honor customs	2,10, 12,16, 22, 28, 30	7	23%
3	Modesty	Modesty, Religious values, Beliefs, Modesty,	8,11,19, 21	4	13%
4	Community	Community, Family respect, Community values	7, 18, 29	3	10%
5	Influence	Cultural influence, Influence, Fusion,	15,17, 26	3	10%
6	Festivals	Festivals, Local artisans, Ancestors Wedding	5, 14, 23, 24	4	13%
7	Work and Daily Attire	Work attire, Comfort	9,20	2	7%

Table 3 Response for Question N° 2

Respondent Number	Response	Key Word
1	In our community, modest clothing is highly valued and shapes fashion choices.	Modesty
2	We prefer brands that offer traditional designs blended with modern elements.	Blended Designs
3	Social norms in our area discourage overly revealing clothing and promote decency.	Decency
4	I notice that people admire styles that respect cultural values while being trendy.	Cultural Values
5	Within my circle, locally made attire is more acceptable than international brands.	Local Preference
6	Our community prioritizes practicality and comfort over extravagant fashion.	Practicality
7	Fashion trends in our area are heavily influenced by what the elders deem appropriate.	Elders' Influence
8	People in my area admire clothing that aligns with religious and cultural standards.	Religious Standards
9	We often follow styles that are common among friends and family, creating a sense of unity.	Unity
10	Social gatherings are where we observe and adopt acceptable fashion trends.	Social Gatherings
11	I think community expectations create a preference for conservative designs.	Conservative Designs
12	We favor brands that highlight our regional identity and cultural pride.	Regional Identity
13	The youth in our community tend to adopt styles influenced by social media, but only if acceptable locally.	Social Media
14	Modern brands are gaining acceptance, but only those that respect our traditions.	Modern Acceptance
15	I feel pressure to wear styles that are considered modest and appropriate by my peers.	Peer Influence
16	Fashion choices are greatly shaped by family values and communal expectations.	Family Values
17	Popular brands in our region are those that combine elegance with simplicity.	Elegance
18	Our community accepts certain global trends only when they are adapted to fit local customs.	Global Adaptation
19	I believe that social norms encourage us to maintain a balance between tradition and modernity in clothing.	Balance
20	People admire brands that use sustainable and locally sourced materials.	Sustainability
21	In my area, flashy or overly colorful attire is generally frowned upon.	Subtlety
22	We prefer styles that allow us to express individuality without breaking cultural norms.	Individuality
23	Clothing choices for formal events are often influenced by the expectations of influential community members.	Formal Expectations
24	Social norms dictate that clothing for women should be both modest and functional.	Women's Modesty
25	I observe that people in our community are drawn to timeless, classic styles.	Timeless Style
26	Fashion trends here are shaped by a combination of local festivals and religious events.	Cultural Events
27	The acceptance of any new fashion trend depends on how well it aligns with our ethical standards.	Ethical Standards
28	We look up to elders in the community to guide us on what is acceptable in fashion.	Elder Guidance
29	Social norms in our area encourage the use of simple, elegant designs for daily wear.	Simplicity
30	I find that community expectations often limit the adoption of bold or experimental styles.	Limitation

Table 4 Thematic classifications for question 2

Serial Number	Thematic Main Key Word	Classified Key Words	Respondent Numbers	Frequency	Percentage
1	Cultural Values	Cultural Values, Regional Identity, Family Values, Elders' Influence	4, 12, 16, 7	4	13.33%
2	Modesty	Modesty, Religious Standards, Women's Modesty, Subtlety, Conservative Designs	1, 8, 24, 21, 11	5	16.67%
3	Blended Designs	Blended Designs, Balance, Timeless Style, Modern Acceptance	2, 19, 25, 14	4	13.33%
4	Social Influence	Social Media, Peer Influence, Social Gatherings, Formal Expectations	13, 15, 10, 23	4	13.33%
5	Tradition and Heritage	Cultural Events, Unity, Simplicity, Elder Guidance	26, 9, 29, 28	4	13.33%
6	Practicality	Practicality, Sustainability, Limitation, Elegance	6, 20, 30, 17	4	13.33%
7	Individuality	Individuality, Ethical Standards, Global Adaptation	22, 27, 18	3	10%
8	Local Preferences	Local Preference, Decency	5, 3	2	6.67%

Table 5 Responses for Question N° 3:

Respondent Number	Response	Key Word
1	I often use social media to explore new fashion trends and it has influenced my choices significantly.	Social Media
2	Online shopping has made it easier for me to access trendy outfits that were not available locally.	Online Shopping
3	We see many people adopting modern styles seen on social media, but it sometimes clashes with our culture.	Cultural Clash
4	Social media helps us stay updated, but it often promotes styles that do not align with our traditions.	Style Updates

5	I feel local artisans are not represented well on online platforms, which limits cultural influence.	Local Representation
6	Online shopping platforms have given us access to a variety of styles that we could not imagine before.	Accessibility
7	My family prefers traditional attire, but I often find myself drawn to modern designs on Instagram.	Modern Designs
8	We believe that technology is a double-edged sword; it brings awareness but also challenges our values.	Value Challenge
9	Social media influencers have a huge role in shaping what we wear and buy these days.	Influencers
10	Online platforms have made buying clothes more convenient, especially for busy professionals like me.	Convenience
11	I think social media over-represents Western styles, which sometimes overshadow our local traditions.	Western Influence
12	I rely on online reviews before making fashion purchases, which has changed how I shop.	Reviews
13	Platforms like Facebook and Instagram have inspired me to experiment with new looks.	Experimentation
14	I noticed that many people in our area follow celebrities on social media and mimic their styles.	Celebrity Influence
15	Online shopping allows us to compare prices, which has made fashion more affordable for many.	Price Comparison
16	My friends and I often share links to fashion items online, which influences what we choose to buy.	Peer Sharing
17	We feel proud when we see local culture highlighted in online campaigns, but it happens rarely.	Cultural Pride
18	Social media has encouraged me to mix traditional and modern styles for a unique look.	Fusion Styles
19	I find that online ads often promote fast fashion, which is not sustainable for our region.	Fast Fashion
20	Online platforms have made fashion accessible to rural areas, bridging the gap with urban trends.	Rural Access
21	I think people are adopting international brands more due to their heavy online presence.	International Brands
22	We need more local brands to establish their presence online to compete with global platforms.	Local Brands
23	I feel that social media showcases a wide range of fashion options but lacks sensitivity to local norms.	Norm Sensitivity
24	Online influencers often encourage impulsive shopping habits, which is a concern.	Impulsive Shopping
25	My family uses online shopping to buy traditional clothes during festivals, which saves time.	Festival Shopping
26	I have learned a lot about mixing and matching clothes through fashion blogs online.	Styling Tips
27	Social media has made people more aware of global trends, which sometimes conflicts with local norms.	Global Trends
28	I appreciate how some online stores now offer customization to reflect local designs.	Customization
29	Social media campaigns promoting cultural events influence my choice of attire for those occasions.	Event Promotion
30	I feel online shopping discounts have encouraged more people to try out new styles.	Discounts

Table 6 Thematic results for Question N° 3

Serial Number	Thematic Main Key Word	Classified Key Words	Respondent Numbers	Frequency	%
1	Social Media Influence	Social Media, Influencers, Celebrity Influence, Global Trends, Peer Sharing	1, 9, 14, 27, 16	5	16.67 %
2	Online Shopping Impact	Online Shopping, Reviews	2, 12	2	6.67 %
3	Cultural Identity	Cultural Clash, Local Representation, Cultural Pride, Event Promotion	3, 5, 17, 29	4	13.33 %
4	Modern Fashion Trends	Modern Designs, Style Updates, Fusion Styles, Styling Tips, Western Influence	4, 7, 18, 26, 11	5	16.67 %
5	Practicality	Convenience, Accessibility, Rural Access, Impulsive Shopping	10, 6, 20, 24	4	13.33 %
6	Local and Traditional Brands	Local Brands, Festival Shopping	22, 25	2	6.67 %
7	Value-Based Challenges	Value Challenge, Fast Fashion, Norm Sensitivity	8, 19, 23	3	10.00 %
8	Economic Influence	Discounts, Price Comparison, International Brands	30, 15, 21	3	10.00 %
9	Innovation and Experimentation	Experimentation, Customization,	13, 28	2	6.67 %

Table 7 Responses for Question N° 4

Respondent Number	Response	Key Word
1	We believe incorporating traditional designs makes our fashion products more appealing.	Traditional Designs
2	I think promoting cultural festivals helps showcase our local fashion identity.	Festivals
3	Our customers appreciate when we align modern trends with cultural heritage.	Heritage Alignment
4	I have noticed that cultural storytelling enhances the value of our products.	Storytelling
5	We focus on designs that reflect the pride of our regional culture.	Regional Pride
6	I feel our marketing campaigns should emphasize respect for cultural traditions.	Cultural Respect

7	Our business incorporates local artisan work to highlight traditional skills.	Local Artisans
8	We align our branding with community expectations to ensure acceptance.	Community Alignment
9	Our customers prefer traditional patterns for special occasions.	Traditional Patterns
10	I think educating customers about the cultural roots of our products improves sales.	Cultural Education
11	We aim to maintain a balance between modern designs and cultural authenticity.	Cultural Authenticity
12	I have seen that highlighting the region's heritage in campaigns draws more interest.	Heritage Highlighting
13	Our focus on sustainable materials aligns with cultural values of simplicity.	Sustainability
14	We prioritize modest designs to match cultural expectations.	Modesty
15	I believe connecting fashion products to local festivals boosts customer engagement.	Local Festivals
16	We use cultural motifs in our branding to make it relatable to the local audience.	Cultural Motifs
17	Our business involves community input to ensure our designs are culturally appropriate.	Community Input
18	We respect cultural sensitivities by avoiding overly modern styles in our promotions.	Cultural Sensitivities
19	I think promoting locally made products fosters a sense of community pride.	Local Products
20	We integrate ancestral themes into our campaigns to honor cultural traditions.	Ancestral Themes
21	Our customers respond well to campaigns that combine storytelling and visuals.	Visual Storytelling
22	I believe offering customized options reflecting cultural values is vital.	Customization
23	Our team engages with cultural experts to ensure authenticity in our campaigns.	Cultural Expertise
24	I have noticed that incorporating historical symbols appeals to older customers.	Historical Symbols
25	Our advertisements highlight the connection between fashion and local festivals.	Festival Connection
26	We focus on promoting the craftsmanship of local designers in our campaigns.	Local Craftsmanship
27	I feel campaigns must address generational differences in cultural preferences.	Generational Balance
28	We promote our products by linking them to cultural pride and identity.	Cultural Identity
29	Our business thrives by collaborating with local artists to create unique designs.	Local Collaboration
30	I believe emphasizing ethical production methods resonates with local cultural values.	Ethical Practices

Table 8 Thematic frequencies for Q N° 4

Serial Number	Thematic Main Key Word	Classified Key Words	Respondent Numbers	Frequency	Percentage
1	Cultural Heritage	Traditional Designs, Heritage Alignment, Ancestral Themes, Historical Symbols, Heritage, Cultural Sensitivities Highlighting	1, 3, 18, 20, 24, 12	6	20.00%
2	Community and Local Involvement	Local Artisans, Community Alignment, Community Input, Local Collaboration, Local Craftsmanship	7, 8, 17, 29, 26	5	16.67%
3	Cultural Pride and Identity	Regional Pride, Cultural Identity, Cultural Respect, Cultural Motifs, Generational Balance	5, 28, 6, 16, 27	5	16.67%
4	Festivals and Traditions	Festivals, Local Festivals, Festival Connection, Traditional Patterns	2, 15, 25, 9	4	13.33%
5	Marketing Approaches	Storytelling, Visual Storytelling, Cultural Education, Customization, Cultural Expertise	4, 21, 10, 22, 23	5	16.67%
6	Ethical and Sustainable Practices	Sustainability, Modesty, Ethical Practices, Local Products, Cultural Authenticity	11, 13, 14, 30, 19	5	16.67%

Table 9 Consolidated Core Categories with Total Frequencies

Core Category	Thematic Grouped Words (Frequency)	Total Frequency	%
Cultural Heritage	Tradition (7), Cultural Identity (7), Cultural Values (4), Tradition and Heritage (4), Cultural Heritage (6)	28	23.33%
Community and Identity	Community (3), Community and Local Involvement (5), Cultural Pride and Identity (5), Social Influence (4)	17	14.17%
Modesty and Ethics	Modesty (4), Ethical and Sustainable Practices (5), Value-Based Challenges (3), Cultural Sensitivities (3)	15	12.50%
Modern Influence	Influence (3), Blended Designs (4), Modern Fashion Trends (5), Social Media Influence (5), Marketing Approaches (5)	22	18.33%
Practicality and Events	Festivals (4), Practicality (4), Work and Daily Attire (2), Local Preferences (2), Festivals and Traditions (4)	16	13.33%
Economic and Local Impact	Local and Traditional Brands (2), Economic Influence (3), Innovation and Experimentation (2), Online Shopping Impact (2), Local Products (3)	12	10.00%
Festivals and Traditions	Local Festivals (4), Festival Connection (4), Ancestral Themes (2)	10	8.33%

ENHANCING GROUP PSYCHOLOGICAL COUNSELLING THROUGH AI-DRIVEN ETHICAL DIGITALISATION

Jieying Li^{1*}, Pengsen Li²

Abstract: This qualitative study explores the integration of Artificial Intelligence (AI) in group psychological counselling within wellness education through an ethical and interdisciplinary framework. Drawing on 30 in-depth interviews with educators and mental health professionals, the research examines perceptions of ethical digitalisation, the application of knowledge graphs for personalised emotional mapping, the role of outcome-based education (OBE) in structuring measurable psychological goals, and the impact of industry-education collaboration in co-developing AI tools. Thematic analysis identified five overarching domains: ethical governance, data-driven personalisation, outcome alignment, collaborative innovation, and cultural responsiveness. Findings reveal both enthusiasm for AI's potential to enhance support and significant concerns regarding privacy, algorithmic bias, institutional barriers, and the need for human-centred design. The study concludes that effective implementation requires robust ethical frameworks, continuous stakeholder engagement, and adaptive educational structures. These insights offer a conceptual foundation for designing AI-supported counselling systems that align with psychological development goals while safeguarding ethical integrity in diverse educational environments.

Keywords: ethical digitalisation, group psychological counselling, knowledge graphs, outcome-based education, industry education collaboration

Mejora de la terapia psicológica grupal mediante la digitalización ética impulsada por IA

Resumen: Este estudio cualitativo explora la integración de la Inteligencia Artificial (IA) en la terapia psicológica grupal dentro de la educación para el bienestar, desde una perspectiva ética e interdisciplinaria. A partir de 30 entrevistas en profundidad con educadores y profesionales de la salud mental, la investigación examina las percepciones sobre la digitalización ética, la aplicación de grafos de conocimiento para la elaboración de mapas emocionales personalizados, el papel de la educación basada en resultados (EBR) en la estructuración de objetivos psicológicos medibles y el impacto de la colaboración entre la industria y la educación en el codesarrollo de herramientas de IA. El análisis temático identificó cinco dominios principales: gobernanza ética, personalización basada en datos, alineación de resultados, innovación colaborativa y sensibilidad cultural. Los hallazgos revelan tanto el entusiasmo por el potencial de la IA para mejorar el apoyo, como importantes preocupaciones respecto de la privacidad, el sesgo algorítmico, las barreras institucionales y la necesidad de un diseño centrado en el usuario. El estudio concluye que una implementación efectiva requiere marcos éticos sólidos, la participación continua de las partes interesadas y estructuras educativas adaptativas. Estas perspectivas ofrecen una base conceptual para el diseño de sistemas de asesoramiento psicológico con apoyo de IA que se alineen con los objetivos de desarrollo psicológico, salvaguardando la integridad ética en diversos entornos educativos.

Palabras clave: digitalización ética, asesoramiento psicológico grupal, grafos de conocimiento, educación basada en resultados, colaboración entre la industria y la educación

Aprimorando o aconselhamento psicológico em grupo por meio de digitalização ética orientada por IA

Resumo: Esse estudo qualitativo explora a integração de Inteligência Artificial (IA) em aconselhamento psicológico em grupo dentro da educação para o bem estar através de uma estrutura ética e interdisciplinar. Com base em 30 entrevistas aprofundadas com educadores e profissionais de saúde mental, a pesquisa examina percepções sobre digitalização ética, a aplicação de gráficos de conhecimento para mapeamento emocional personalizado, o papel da educação baseada em desfechos (OBE) na estruturação de objetivos psicológicos mensuráveis e o impacto da colaboração entre indústria e educação no desenvolvimento conjunto de ferramentas de IA. Análise temática identificou cinco domínios abrangentes: governança ética, personalização orientada por dados, alinhamento de resultados, inovação colaborativa e sensibilidade cultural. Os achados revelam tanto entusiasmo para o potencial da IA para aprimorar o apoio quanto preocupações significativas com respeito à privacidade, vies algorítmico, barreiras institucionais e a necessidade de um design centrado no ser humano. O estudo conclui que a implementação efetiva requer contexto ético robusto, engajamento contínuo das partes interessadas e estruturas educacionais adaptativas. Esses insights oferecem uma base conceitual para o desenvolvimento de sistemas de aconselhamento apoiados por IA que estejam alinhados com os objetivos de desenvolvimento psicológico, ao mesmo tempo que salvaguardam a integridade ética em diferentes ambientes educacionais.

Palavras chave: digitalização ética, aconselhamento psicológico em grupo, gráficos de conhecimento, educação baseada em desfechos, colaboração entre indústria e educação

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Introduction

The increasing global demand for mental health support has established group psychological therapy as an essential element of wellness education, especially in the education sector(1). The evolving mental health requirements of students, educators, and administrators necessitate the incorporation of modern digital technologies, particularly artificial intelligence (AI), which serves as a potent facilitator of scalable, responsive, and contextually pertinent therapies. The swift implementation of AI-driven solutions prompts substantial ethical concerns related to data protection, consent, algorithmic transparency, cultural sensitivity, and the psychological effects of human-computer interaction(2, 3). Resolving these difficulties necessitates a deliberate and interdisciplinary approach that integrates technical innovation with ethical accountability and educational objectives(4,5).

The research aims to investigate how artificial intelligence can ethically enhance group counselling methodologies while respecting the values and needs of diverse educational groups.

This framework is developed through a qualitative research design utilising in-depth, semi-structured interviews. The research encompassed 30 specialists from China, South Korea, Pakistan, and Iran, chosen by purposive sampling based on their expertise in wellness education, mental health, and educational technology. This varied sample guaranteed cultural and institutional diversity in viewpoints toward AI integration. Participants exhibited variations in data ethics, AI adoption rates, counselor training, and governance structures, enhancing the study's comparative rigor. The data gathering process adhered to rigorous study guidelines established beforehand by the primary investigator, guaranteeing complete compliance with international ethical standards for qualitative research.

The ethical perspective is crucial to this research and was meticulously analyzed throughout the study, especially in relation to wellness education. The ethical dimension encompasses questions of informed consent, digital well-being, equitable access, inclusion, and the appropriate utilisation of AI tools. The study examines the use of ethical

digitalisation in group counselling settings while maintaining the integrity and psychological safety of participants. To uphold the integrity and psychological safety of all participants, we secured informed consent before each interview, explicitly detailing the study's goal, the voluntary nature of participation, and the guarantee of anonymity. Interviews were performed in compliance with institutional ethical norms, ensuring respectfulness, non-invasiveness, and support for participants' emotional well-being.

The suggested framework incorporates knowledge graphs to assist AI in delineating emotional states, social dynamics, and counselling pathways(6). It utilises outcome-based education (OBE) to synchronise counselling techniques with quantifiable objectives for emotional and cognitive development. Moreover, it underscores the necessity of collaboration between industry and education to guarantee that the AI tools created are not just innovative but also practical, scalable, and pertinent to actual educational environments(7).

This study aims to provide a theoretical contribution and practical suggestions for institutions seeking to improve group psychological therapy through ethical, AI-driven digitalisation by utilising interdisciplinary theories and lived experiences. The results are anticipated to guide educational policy, enhance curriculum development in wellness education, and enrich the international dialogue on responsible AI in mental health services.

Research Questions

1. How do educators and mental health professionals within the wellness education sector perceive the ethical implications of integrating AI into group psychological counselling? Focus: *Ethical digitalisation in counselling*
2. In what ways can knowledge graphs be utilised to enhance the effectiveness and personalisation of AI-supported group psychological counselling in wellness education? Focus: *Use of knowledge graphs for AI implementation*
3. How can outcome-based education principles

be embedded into AI-driven group counselling models to support measurable emotional and psychological development among students?
Focus: *Integration of outcome-based education*

4. What are the perceived benefits and challenges of fostering industry-education collaboration in the development and deployment of AI tools for group psychological counselling in wellness education?
Focus: *Role of industry-education collaboration*

Literature review

This literature review aims to investigate and critically assess existing research across several categories pertinent to the ethical digitisation of group psychological counselling in wellness education. The literature review integrates current research from educational psychology, artificial intelligence in mental health technologies, and ethical digital innovation. The aim is to establish a unified framework that connects disparate disciplines, facilitating a comprehensive comprehension of AI's responsible and effective integration into group psychological counselling in educational settings. Some studies emphasise the digital transformation of counselling services, showcasing the advantages of automation, personalisation, and scalability (8). In contrast, others express concerns regarding the dehumanisation of treatment, ethical issues, and the potential for technology reliance. Conversely, studies in wellness education prioritise comprehensive methods for student development, incorporating emotional, cognitive, and social advancement through organised support initiatives (9). Nonetheless, there exists minimal integration between wellness education frameworks and nascent AI applications, particularly in group counselling settings. This review situates itself at the convergence of disparate literatures, seeking to identify deficiencies, compare theoretical perspectives, and provide a cohesive basis for establishing an ethical, AI-enhanced counselling framework specifically designed for the wellness education sector (10).

Group Psychological Counselling in Educational Contexts

Group psychological counselling has emerged as an essential element of wellness education, provid-

ing students with a supportive setting to confront emotional, psychological, and social issues collectively. Research indicates that group counselling fosters a sense of belonging, emotional articulation, and peer affirmation, which are particularly beneficial in educational environments aimed at holistic development (11). Diverse therapeutic models—such as cognitive-behavioural group therapy, humanistic methods, and solution-focused group interventions—have been tailored to accommodate the distinct dynamics of educational institutions (12, 13). These paradigms prioritise contact, empathy, and collective experiences, promoting individual understanding and community unity. Traditional delivery methods frequently encounter obstacles, including a shortage of experienced facilitators, time limits, stigma around help-seeking, and uneven participation. Certain studies suggest that in extensive educational environments, maintaining confidentiality and regulating group dynamics can become complex. These limitations underscore the necessity for creative solutions, such as AI-assisted tools, that can augment established approaches while improving the accessibility, consistency, and scalability of group counselling in wellness education (14).

Artificial Intelligence in Mental Health and Education

The incorporation of artificial intelligence into mental health services has created revolutionary opportunities, especially in psychological counselling. AI solutions, including virtual counselling agents, emotion-recognition systems, predictive analytics, and adaptive learning platforms, have shown promise in enhancing both individual and group counselling processes. In educational environments, AI-assisted therapies are progressively employed to assess student well-being, provide tailored mental health resources, and mimic therapeutic interactions (15). When ethically built and culturally adapted, AI systems can provide scalable psychological support through timely interventions, especially in underprivileged or high-demand educational settings. Recent research indicates that such systems have the potential to enhance access to mental health resources while alleviating the operational burden on human counsellors. Nonetheless, although some studies highlight the advantages of efficiency, scalability,

and data-driven insights, others express considerable apprehension regarding the ethical and emotional ramifications of AI-driven therapy. Risks encompass violations of confidentiality, algorithmic bias, absence of human empathy, and excessive dependence on technology in emotionally complex scenarios. The literature presents a range of viewpoints: some scholars advocate for AI as a beneficial adjunct to human-driven psychological services, highlighting its capacity to improve scalability and personalisation; others warn against its swift deployment without comprehensive ethical, clinical, and contextual assessment. This disparity underscores the necessity for a balanced, interdisciplinary approach to integrating AI into mental health care systems.. These discussions highlight the need for ethically based frameworks that guarantee Wellness education has intricate emotional, psychological, and ethical aspects. Consequently, it necessitates deliberate and contextually aware interventions emphasizing safety, inclusion, and psychological well-being. This requires a careful and evidence-based use of technology, such as AI, in wellness counselling(16, 17).

Ethical Digitalisation in Wellness Education

The ethical digitisation of wellness education has been a pivotal concern as institutions progressively incorporate AI technologies into mental health and counselling services. Central to digital wellness are ethical values like respect for autonomy, data privacy, informed consent, and emotional safety, all of which are crucial when engaging with vulnerable groups such as students in need of psychiatric care. The incorporation of AI into these services presents intricate ethical dilemmas. Research highlights concerns such as algorithmic bias, where AI systems may yield distorted results due to unrepresentative data, and privacy threats arising from the collection and analysis of sensitive psychological data(18, 19).

Moreover, concerns about user autonomy are significant, especially when AI systems begin to influence decision-making in therapeutic contexts. Academics underscore the necessity of culturally sensitive and inclusive digital methodologies, asserting that AI tools should be developed to cater to varied social, emotional, and linguistic contexts to prevent marginalization(20). Despite increasing

awareness, the literature indicates a deficiency in standardised ethical frameworks and institutional norms to direct the responsible application of AI in wellness education. This gap requires the formulation of context-specific ethical principles that address technology accountability while aligning with the values and objectives of wellness-oriented educational settings(21, 22).

Knowledge Graphs in AI and Psychological Applications

Knowledge graphs, as semantic technologies designed to depict structured relationships among concepts, have demonstrated interesting applications in the fields of psychology and behavioral sciences. These AI tools allow machines to comprehend and contextualise human experiences by mapping emotional states, behaviours, and psychological constructs via interconnected data points. In psychological applications, knowledge graphs enhance understanding of mind, emotion, and social dynamics by integrating diverse information sources, such as verbal replies, facial expressions, and digital behaviour, into cohesive semantic networks. Recent research has examined their effectiveness in modelling personal emotional trajectories and group dynamics, particularly in therapeutic settings where comprehension of social influence, empathy, and relational patterns is essential(23, 24).

In group therapy contexts, knowledge graphs can elucidate the relationships among participants' common issues or emotional states, providing counsellors with a real-time, data-informed framework for directing therapies. The application of knowledge graphs, often utilised in medical or informational retrieval systems, to mental health and counselling contexts signifies a groundbreaking multidisciplinary transition. Nonetheless, experts acknowledge problems, including the difficulty of encapsulating nuanced human emotions within rigid semantic frameworks and ensuring the interpretability and transparency of the AI's recommendations. Nevertheless, the capacity of knowledge graphs to enhance psychological modelling and group counselling techniques remains an expanding field of inquiry, particularly within ethically principled educational settings(25, 26).

Outcome-Based Education (OBE) and Its Application in Counselling

Outcome-Based Education is a learner-centred approach that emphasizes the achievement of clearly defined learning outcomes, guiding both instructional strategies and assessment practices. Traditionally utilised in academic and skill-based learning settings, OBE has received increasing scholarly attention over time for its potential to improve educational accountability and learner-centric assessment frameworks. Academics contend that incorporating OBE concepts into group psychological counselling offers a systematic framework for establishing therapeutic objectives, monitoring emotional advancement, and assessing the efficacy of interventions. By pinpointing specific emotional or behavioural outcomes, such as enhanced self-awareness, resilience, or group communication, counselling sessions can be synchronised with overarching educational goals(27, 28).

The utilisation of AI in this context optimises the process by providing tools that assess progress via sentiment analysis, behaviour monitoring, and feedback mechanisms, facilitating real-time modifications to counselling tactics. Some studies commend the integration of OBE and AI-assisted counselling for enhancing responsibility and personalisation, while others warn against oversimplifying intricate emotional development into quantitative measures. Nevertheless, the integration of OBE principles with AI technology presents considerable potential for developing more focused, adaptive, and results-oriented psychological support systems in education(29, 30).

Industry-Education Collaboration in Digital Innovation

Collaboration between industry and education in digital innovation has emerged as a vital catalyst for technical progress in educational and psychological support systems. Diverse collaboration models—spanning strategic partnerships, joint research initiatives, and co-developed platforms—illustrate how educational institutions and the technology sector can work together to tackle complex issues such as digital mental health and the integration of ethical AI. These collaborations

have resulted in the co-creation of AI tools that are both technically sound and rooted in pedagogical and psychological ethics, ensuring conformity with educational principles and student well-being(31).

The success of such collaborations depends on numerous critical variables, including mutual trust, aligned objectives, honest communication, and the incorporation of diversified skills. Research identifies prevalent problems, including misaligned priorities, data governance complications, and power disparities that may obstruct fair development and execution. Despite these challenges, when well managed, such partnerships can yield new, context-specific solutions that improve the digital counselling framework in educational environments while upholding ethical standards and inclusion(32).

Interdisciplinary Frameworks in Education and Technology

Interdisciplinary frameworks that integrate education, psychology, and computer science are crucial for creating holistic solutions in technologically advanced learning and counselling settings. Psychological theories highlight human growth, emotional intelligence, and behavioural modification, whereas educational theory offers learner-centred pedagogy and outcome-based evaluation. Computer science, especially via artificial intelligence, facilitates data-driven decision-making, automation, and adaptive technology(33, 34).

Although current frameworks like socio-technical systems, digital learning ecosystems, and AI-informed educational interventions strive to amalgamate these fields, they frequently fail to encompass the intricate nuances of human emotions, ethical implications, and contextual variability, particularly in the realm of mental health and wellness education(13, 35). Numerous frameworks either rely excessively on technological competencies without adequate psychological foundations or concentrate only on academic results while neglecting emotional health. This highlights a substantial deficiency in the existing literature: an absence of comprehensive, morally grounded, and pragmatically applicable models that effectively synthesise ideas from all three domains (35, 36).

Rectifying this deficiency is essential for promoting AI-enhanced group psychological counselling in wellness education, guaranteeing that forthcoming frameworks are multidisciplinary both in theory and application(37).

Global and Cross-Cultural Perspectives on Wellness and Ethics

Global and cross-cultural perspectives on wellness and ethics reveal significant disparities in the understanding, practice, and institutionalization of psychological well-being and counseling across various nations. In certain areas, wellness education prioritises mindfulness, community support, and holistic development, whilst others implement more clinical, regimented methodologies based on medical or behavioural frameworks. The disparities are additionally manifested in the ethical standards regulating psychiatric therapy, wherein cultural norms influence concepts of privacy, autonomy, emotional expression, and the authority's role in therapeutic partnerships(38, 39).

AI integration in various educational environments may be affected by cultural orientations, such as collectivism and individualism, which shape counseling expectations, privacy standards, and participation behaviors. Collectivist societies often prioritize communal welfare and collaborative decision-making, whereas individualistic cultures emphasize personal autonomy and privacy. These distinctions can influence the perception and utilization of AI-driven counseling solutions(40, 41). This global viewpoint emphasises the necessity for cross-cultural research and policy discussions that connect technical advancement with ethical awareness in wellness education systems(42, 43).

Methodology of the Study

The research utilized a semi-structured qualitative interview methodology with 30 educators and mental health practitioners engaged in wellness education across several institutions. The interview guide included four primary open-ended questions, each designed to investigate a significant thematic area pertinent to the study's interdisciplinary framework: (1) ethical digitalization in AI-assisted counseling, (2) utilization of knowledge graphs, (3) incorporation of outcome-

based education, and (4) collaboration between industry and education.

The questions were intentionally expansive, allowing participants to contemplate, elaborate, and contextualize their answers according to personal experiences, institutional practices, and professional viewpoints. Interviewers employed probing approaches to enhance the exploration of each subject area, frequently leading to discussions lasting 30 to 45 minutes per participant. This method conforms to established qualitative approaches, wherein the depth is attained through the narrative richness and theme saturation rather than solely through the number of structured prompts(44). The research is based on an interpretivist framework that highlights the collaborative creation of meaning between the researcher and the participants(45).

Research Context and Parameters

The research was carried out in many nations, concentrating primarily on organisations and professionals engaged in the wellness education field. Cross-cultural design enhances the comprehension of the interpretation and implementation of ethical AI-driven innovations in group psychological counselling across various educational environments (45, 46).

Participants and Sampling Methodology

Thirty participants were selected using purposive sampling, focusing on persons directly engaged in wellness education and psychological therapy inside educational institutions. Participants comprised counsellors, educators, academic psychologists, digital education professionals, and institutional policy developers. The varied responses gathered from culturally and professionally diverse participants provided a broad understanding of how AI tools are perceived and applied within group psychological counselling across different wellness education contexts.

Method of Data Collection

Data was gathered via semi-structured interviews, facilitating the exploration of specific themes while ensuring consistency among participants

(47). Each interview lasted 45 to 60 minutes and was performed either in person or over secure video conferencing services, contingent upon the participant's location and preference. Interview enquiries centred on participants' experiences with group therapy, perspectives on AI-driven technologies, attitudes towards ethical digitalisation, understanding of multidisciplinary integration, and institutional support systems.

Interview Protocol and (47)s

- An interview guide was developed based on the key thematic areas of the research:
- Role of AI in group counselling processes
- Ethical implications and cultural considerations
- Use of knowledge graphs in psychological modelling
- Outcome-Based Education and Counselling Integration
- Industry-education collaboration. All interviews were recorded (with prior consent) and later transcribed verbatim for thematic analysis.

Data Analysis

Thematic analysis was used to interpret the qualitative data. The analysis followed Braun and Clarke's six-phase approach(48):

- Familiarisation with data
- Generating initial codes
- Searching for themes
- Reviewing themes
- Defining and naming themes
- Producing the report

NVivo software was used to assist with organizing and coding qualitative data. Patterns, themes, and categories were developed inductively to ensure authenticity and coherence with participants' narratives.

Reliability and Precision

Member verification was conducted to establish

trustworthiness, allowing participants to access summaries of their comments for accuracy confirmation. Transferability was preserved by comprehensive descriptions of the environment, participants, and methodologies employed. Dependability was guaranteed via a comprehensive audit trail of all research procedures, while confirmability was addressed through the maintenance of reflective journals to track researcher bias(49).

Ethical Considerations

This research was conducted in accordance with the ethical guidelines governing studies involving human participants. Ethical approval was acquired from a participating university in Pakistan(50).

All participants received an informed consent form detailing the study's objectives, methodologies, potential risks, and their rights, including the option to voluntarily participate and withdraw at any point. Anonymity and confidentiality were strictly maintained through several precautions. All participant data were pseudonymized throughout transcription and analysis, stored on encrypted, password-protected devices, and accessible solely to the core study team. No personally identifying information was documented or revealed at any study phase.

Data Analysis³

Ethical digitalisation in counselling

Table 1 and Table 2 provide a thematic analysis of interview responses regarding how educators and mental health professionals within the wellness education sector perceive the ethical implications of integrating AI into group psychological counselling, with a focus on ethical digitalisation. The most frequently cited theme was Ethical Governance (23.3%), which encompasses concerns around oversight, policy boundaries, institutional guidelines, protocol development, ongoing monitoring, and system alignment. This reflects a strong emphasis on establishing structured and accountable frameworks to manage AI ethically within counseling contexts. A human-centered approach was closely followed, with 20%, highlighting the importance of empathy, human connection, in-

³ Todas las tablas se publican luego de las referencias.

clusion, dialogue, support, and trust in therapeutic environments, as well as the professionals' desire to retain these values alongside technological tools. Privacy and data ethics, as well as algorithmic fairness, were both noted at 13.3%, indicating substantial concern over issues such as data security, consent, confidentiality, transparency, and AI biases—factors that could significantly impact the integrity and equity of digital counseling interventions. Meanwhile, Cultural Sensitivity, Educational Integration, and Critical Reflection each accounted for 10% of the responses, underscoring the need to adapt AI ethically across diverse cultural contexts, integrate interdisciplinary training, and maintain a critical stance toward the limitations and risks of automation. Overall, the data reveal a multi-dimensional awareness among practitioners, with governance and human values emerging as top priorities in ethically navigating AI in group counseling.

Use of knowledge graphs for AI implementation

The analysis of Table 3 and Table 4 reveals that knowledge graphs play a multifaceted role in enhancing AI-supported group psychological counseling within wellness education. The most frequently cited thematic areas—Personalization & Adaptability, Emotional & Behavioral Mapping, Semantic & Contextual Accuracy, AI Decision Support, and Data Structuring & Intelligence—each with a 16.7% share, highlight the core strengths of knowledge graphs in enabling tailored, emotionally intelligent, and data-informed counseling processes. These areas collectively emphasize how knowledge graphs support dynamic, student-specific interventions while maintaining therapeutic coherence and ethical alignment. Slightly less frequent but still important, Group & Peer Interaction (13.3%) reflects the value of understanding interpersonal dynamics, while Cultural Sensitivity (3.3%) suggests an area needing more focus in future applications. Overall, the findings indicate that knowledge graphs are central to creating responsive, ethical, and effective AI-driven counseling environments in wellness education.

Integration of outcome-based education

Tables 5 and 6 provide an insightful analysis of how outcome-based education (OBE) principles

can be integrated into AI-driven group counseling models within the wellness education sector. The thematic word “Goal-Setting & Alignment” (20%) captures the necessity for clear learning outcomes, goal-setting processes, and aligning counseling sessions with the broader educational curriculum to guide the therapeutic process. The “Measurement & Evaluation” theme (20%) highlights the need for concrete, measurable goals, indicators, and performance metrics such as psychological KPIs and rubrics, ensuring that emotional and psychological progress is tracked and evaluated systematically. The theme “Data-Driven Adaptation” (20%) reflects the role of AI in continuously adapting the counseling approach based on real-time data, using progress tracking, analytics, feedback loops, and AI-driven milestones to tailor sessions to individual student needs. Finally, the “Psychological Competency & Development” theme (40%) emphasizes the integration of competencies such as social-emotional learning (SEL) standards, behavioral trends, and holistic emotional development assessment tools, which are critical in fostering overall psychological well-being. The findings underscore the holistic and adaptable nature of AI-supported counseling models, designed to track and enhance student development while aligning with OBE principles.

Interview Responses – Industry-Education Collaboration

The analysis of Table 7 and Table 8 reveals a nuanced understanding of the perceived benefits and challenges of fostering industry-education collaboration in the development and deployment of AI tools for group psychological counselling in wellness education. The most dominant themes, each with a 16.7% frequency, are Strategic Co-Development and Ethical & Privacy Considerations. This indicates that respondents highly value collaborative design, pilot testing, and feedback mechanisms with industry, while also expressing deep concerns over ethical boundaries, data ownership, and the risk of commercialization overpowering student welfare.

Institutional Barriers (13.3%) and Infrastructure & Innovation (13.3%) were highlighted as key challenges, with issues such as unclear policies, communication gaps, and a lack of readiness in

educational institutions to accommodate rapid tech advancements. Educational Alignment (13.3%) also emerged as a vital theme, pointing to the importance of harmonizing technological innovation with curricular relevance and inclusivity. On the opportunity side, Professional Development (10%) reflects how such collaborations can provide mentorship, exposure, and training for educators and counselors.

Less frequently mentioned but still notable were Resource Constraints (6.7%) and Governance & Regulation (6.7%), indicating concerns about funding sustainability and the need for structured oversight frameworks. Cultural Collaboration (3.3%), though least mentioned, highlights an essential aspect—balancing pedagogical values with technological input while ensuring mutual respect.

Final Thematic Grouping into 5 Core Key Words

The final thematic grouping table 9 provides a comprehensive synthesis of insights derived from the study, aligning closely with the research title, “Enhancing Group Psychological Counselling through AI-Driven Ethical Digitalisation: An Interdisciplinary Framework Integrating Knowledge Graphs, Outcome-Based Education, and Industry-Education Collaboration.” The most emphasized theme, AI Intelligence & Data Structuring (30%), reflects participants’ recognition of the need for technically sound AI systems that can deliver contextual accuracy, fairness, predictive insights, and robust data tracking within group counselling. Ethical & Human-Centered Governance (20%) follows closely, highlighting essential concerns around trust, oversight, and data ethics—underscoring that technological advancement must be balanced with human dignity and accountability. Personalization & Psychological Development (20%) emphasizes that AI must enhance emotional support, social-emotional learning, and individualized development, echoing the core objective of psychological counselling. Strategic Collaboration & Institutional Integration (18.3%) brings attention to the enabling role of joint efforts between industry and education sectors, pointing to the infrastructural, cultural, and policy-based mechanisms necessary for sus-

tainable implementation. Lastly, Goal-Oriented Counseling Models (11.7%) reinforce the role of outcome-based education in designing AI tools that align with measurable developmental goals. Collectively, these thematic pillars affirm the need for an ethical, personalized, technically advanced, and collaboratively implemented AI framework for group psychological counselling in wellness education.

Discussions and recommendations

This study’s findings highlight the urgent necessity for creating morally robust, individualized, and cooperative frameworks for incorporating AI into group psychological counselling in wellness education. The rise of fundamental topics such as AI Intelligence and Data Structuring, Ethical and Human-Centered Governance, and Strategic Collaboration indicates the diverse expectations that educators and mental health professionals hold for AI systems. Participants demonstrated robust endorsement for the utilization of knowledge graphs to improve semantic precision and contextual comprehension, facilitating AI in the mapping of emotions and behaviors within dynamic group environments. Moreover, outcome-based education (OBE) has arisen as an effective framework for organizing goal-directed, quantifiable counseling sessions. Nonetheless, apprehensions about prejudice, data exploitation, autonomy, and institutional preparedness suggest that the implementation of AI requires meticulous regulation and ongoing oversight. Collaboration between educational institutions and the technology sector is viewed as both an opportunity and a challenge; successful partnerships can foster innovation, however, also necessitate mutual ethical standards, professional growth, and infrastructural coherence.

This study presents both an empirical exploration and a conceptual framework that advocate for a systematic and interdisciplinary approach to the ethical development of AI tools for group psychological counselling in wellness education, grounded in qualitative insights from international experts. AI systems must incorporate ethical rules, encompassing privacy protections, bias reduction methods, and means for human monitoring. Secondly, knowledge graphs and outcome-oriented educational frameworks must be strategically align-

ned to customize learning trajectories, monitor psychological advancement, and inform intervention strategies. Third, capacity-building initiatives must be institutionalized, emphasizing the training of educators and mental health practitioners in AI literacy and ethical application. Ultimately, the partnership between industry and education must be institutionalized via co-development laboratories, joint governance frameworks, and policy agreements that guarantee AI tools prioritize human-centered objectives over commercial interests. Collectively, these ideas provide a framework for ethically guided, flexible, and results-oriented AI inclusion within the wellness education landscape.

Conclusion

This study emphasizes the revolutionary capacity of AI-driven ethical digitalization in improving group psychological counseling within wellness education. Integrating knowledge graphs, outcome-based education principles, and promoting industry-education collaboration enables the invention of AI solutions that provide individualized, measurable, and ethically sound mental health care. Educators and mental health professionals underscore the significance of ethical governance, emotional intelligence, and interdisciplinary innovation in the evolution of digital counseling. Notwithstanding the excitement surrounding AI's potential, apprehensions over privacy, bias, institutional preparedness, and the threat of dehumanisation linger. The efficacy of AI in psychological counselling relies on both technological progress and a collaborative, morally sound framework that emphasises student welfare, emotional growth, and responsible innovation. This research proposes an exploratory framework informed by thematic insights from international experts, aimed at guiding ethically responsible development of AI-supported group psychological counselling within educational environments.

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Table 1 Ethical digitalisation in counselling

Respondent N°	Interview Response	Keyword
1	I believe ethical oversight is crucial when using AI in any therapeutic setting.	Oversight
2	We are cautious about how AI might unintentionally replace human empathy in group therapy.	Empathy
3	I'm concerned about students' data being misused by AI platforms.	Data Security
4	We ensure transparency in how AI tools process and use participant data.	Transparency
5	I support AI integration, but only with clear ethical boundaries.	Boundaries
6	We struggle with the lack of ethical guidelines tailored for AI in education-based counseling.	Guidelines
7	I find it ethically problematic if students aren't informed how AI evaluates their emotions.	Consent
8	We aim to maintain confidentiality even when digital tools are involved.	Confidentiality
9	I see bias as a serious ethical concern in AI-driven psychological models.	Bias
10	We must be culturally sensitive when developing AI tools for diverse student populations.	Sensitivity
11	I've noticed that some AI systems lack emotional context, which raises ethical red flags.	Context
12	We teach students how AI is used in counseling to foster informed participation.	Awareness
13	I think AI can help, but we must not ignore the human aspect of psychological care.	Humanization
14	We're still exploring how to align AI features with our institutional ethics policies.	Alignment
15	I believe ethical integration starts with training educators and therapists on AI tools.	Training
16	We constantly evaluate the fairness of AI-based group assessments.	Fairness
17	I am skeptical of using AI in areas involving sensitive emotional expression.	Skepticism
18	We believe ethical AI use depends on continuous monitoring and updating of algorithms.	Monitoring
19	I've raised concerns about how AI may reinforce stereotypes in group settings.	Stereotypes
20	We discuss AI ethics with our students to create a shared understanding of its implications.	Dialogue
21	I've seen ethical dilemmas arise when decisions are fully automated without counselor input.	Autonomy
22	We set clear protocols for ethical review before any AI implementation.	Protocols
23	I feel student voices are often missing in ethical decisions about AI use.	Inclusion
24	We are in favor of AI as long as it supports, not replaces, human counselors.	Support
25	I fear AI may desensitize the counseling process if not used carefully.	Desensitization
26	We've established ethical checkpoints during every AI tool deployment in group sessions.	Checkpoints
27	I appreciate the speed of AI but remain concerned about its moral limitations.	Limitations
28	We make sure to include multidisciplinary perspectives when assessing AI ethics.	Multidisciplinarity
29	I think AI brings efficiency, but we must be wary of its impact on student trust.	Trust
30	We follow global ethical standards but tailor them to our student population.	Localization

Table 2 Thematic issues highlight for Q2

Thematic Word	Grouped Keywords	Frequency	
Ethical Governance	Oversight, Boundaries, Guidelines, Protocols, Checkpoints, Monitoring, Alignment	7	23.3%
Privacy & Data Ethics	Data Security, Consent, Confidentiality, Transparency	4	13.3%
Human-Centered Approach	Empathy, Humanization, Inclusion, Dialogue, Support, Trust	6	20.0%
Algorithmic Fairness	Bias, Fairness, Stereotypes, Limitations	4	13.3%
Cultural Sensitivity	Sensitivity, Context, Localization	3	10.0%
Educational Integration	Awareness, Training, Multidisciplinarity	3	10.0%
Critical Reflection	Skepticism, Desensitization, Autonomy	3	10.0%

Table 3 Use of knowledge graphs for AI implementation

Respondent N°	Interview Response	Keyword
1	I use knowledge graphs to link emotional patterns with relevant group interventions.	Emotional Mapping
2	We found that knowledge graphs help personalize therapy sessions by tracking behavioral trends.	Personalization
3	I think knowledge graphs improve the contextual relevance of AI responses during group counseling.	Contextualization
4	We have built semantic maps that connect symptoms to coping strategies in group sessions.	Semantic Linking
5	I rely on structured data from knowledge graphs to understand peer interactions in therapy groups.	Group Dynamics
6	We noticed that knowledge graphs adapt better to individual student wellness profiles.	Adaptability
7	I believe they make AI more intuitive and emotionally intelligent.	Emotional Intelligence
8	We designed a system that predicts emotional needs through linked data in knowledge graphs.	Prediction
9	I use them to identify recurring issues across multiple students in wellness programs.	Pattern Recognition
10	We think knowledge graphs help maintain personalized progress tracking in counseling.	Progress Tracking
11	I see potential in using them to map therapeutic goals and student learning outcomes.	Goal Mapping
12	We've used knowledge graphs to ensure relevance in AI's therapeutic recommendations.	Relevance

13	I integrate them into psychological modeling to enhance response depth.	Modeling
14	We use them to personalize group dialogue based on shared concerns.	Group Dialogue
15	I find their visual nature helps both therapists and students understand emotional pathways.	Visualization
16	We created a student mental health database linked via knowledge graph relations.	Relational Database
17	I applied them to trace behavioral improvements over therapy sessions.	Behavioral Trends
18	We aligned our wellness framework with knowledge-based mental health taxonomy.	Taxonomy Integration
19	I use them to recommend personalized wellness resources.	Resource Mapping
20	We leverage semantic technologies to ensure the AI responses reflect nuanced emotional states.	Semantic Accuracy
21	I like how knowledge graphs help maintain coherence in multi-student counseling scenarios.	Coherence
22	We focus on personalized knowledge links between therapy milestones.	Therapy Milestones
23	I find it easier to design AI responses when graphs show student learning-emotional patterns.	Learning Patterns
24	We connect AI decision paths to ethical models using a knowledge graph backbone.	Ethical Alignment
25	I've used them to prevent repetitive errors in AI responses.	Error Reduction
26	We enhance peer-to-peer support by understanding common behavior nodes.	Peer Behavior
27	I think these graphs help us make emotionally informed decisions.	Emotional Insight
28	We use them to link cultural contexts with therapy relevance.	Cultural Relevance
29	I appreciate their ability to dynamically adapt based on ongoing group input.	Dynamic Adjustment
30	We build evolving therapy models from cumulative graph data.	Evolving Models

Table 4 Thematic frequency and percentage for Q 2

Thematic Word	Grouped Keywords	Frequency	Percentage
Personalization & Adaptability	Personalization, Adaptability, Progress Tracking, Resource Mapping, Dynamic Adjustment	5	16.7%
Emotional & Behavioral Mapping	Emotional Mapping, Emotional Intelligence, Emotional Insight, Behavioral Trends, Learning Patterns	5	16.7%
Semantic & Contextual Accuracy	Semantic Linking, Semantic Accuracy, Contextualization, Relevance, Visualization	5	16.7%
Group & Peer Interaction	Group Dynamics, Group Dialogue, Peer Behavior, Coherence	4	13.3%
AI Decision Support	Prediction, Modeling, Goal Mapping, Therapy Milestones, Ethical Alignment	5	16.7%
Data Structuring & Intelligence	Pattern Recognition, Relational Database, Taxonomy Integration, Error Reduction, Evolving Models	5	16.7%
Cultural Sensitivity	Cultural Relevance	1	3.3%

Table 5 Integration of outcome-based education

Respondent N°	Interview Response	Keyword
1	I use learning outcomes to guide counseling goals and track student progress.	Learning Outcomes
2	We align our emotional support strategies with predefined development objectives.	Alignment
3	I believe measurable goals help personalize group counseling sessions effectively.	Measurable Goals
4	We map counseling themes to specific psychological competencies.	Competencies
5	I structure group activities based on behavioral milestones.	Milestones
6	We assess students' emotional growth using predefined indicators.	Indicators
7	I integrate reflective practices to evaluate both counseling and learning outcomes.	Reflection
8	Our AI tools track psychological progress in line with educational objectives.	Progress Tracking
9	I co-design counseling objectives with students to align with OBE goals.	Co-Design
10	We use AI data analytics to evaluate emotional learning outcomes.	Data Analytics
11	I embed feedback loops to adjust sessions based on emotional outcomes.	Feedback Loops
12	We use outcome-based rubrics to evaluate group counseling impact.	Rubrics
13	I find that goal-setting improves both focus and accountability in counseling.	Goal-Setting
14	Our AI system categorizes interventions based on outcome frameworks.	Intervention Mapping
15	I ensure each session has clear learning goals and psychological objectives.	Session Goals
16	We use emotional assessment tools that match learning outcomes.	Assessment Tools
17	I adapt counseling based on student achievement data from other academic areas.	Adaptation
18	We integrate SEL standards to ensure psychological development is measurable.	SEL Standards
19	I think aligning emotional growth with curriculum objectives improves holistic development.	Holistic Development
20	We continuously evaluate group dynamics in light of educational outcomes.	Group Dynamics
21	I find AI useful in mapping outcome-based behavioral trends.	Behavioral Trends
22	Our feedback system enables iterative improvements in both learning and emotional support.	Iteration
23	I link emotional objectives with cognitive development outcomes.	Cognitive Link
24	We incorporate psychological KPIs to evaluate AI-driven counseling results.	Psychological KPIs
25	I rely on performance metrics to track growth in soft skills.	Performance Metrics
26	We plan counseling curriculum with emotional outcomes as a foundation.	Counseling Curriculum
27	I use digital portfolios to track students' emotional learning journey.	Digital Portfolio

28	We embed milestones within AI algorithms to monitor student development.	AI Milestones
29	I analyze counseling output based on emotional competency rubrics.	Competency Rubrics
30	We co-assess student emotional development alongside academic advisors.	Co-Assessment

Table 6 Thematic words for Q 3

Thematic Word	Grouped Keywords	Frequency	Percentage
Goal-Setting & Alignment	Learning Outcomes, Alignment, Goal-Setting, Counseling Curriculum, Session Goals	6	20.0%
Measurement & Evaluation	Measurable Goals, Indicators, Rubrics, Psychological KPIs, Performance Metrics	6	20.0%
Data-Driven Adaptation	Progress Tracking, Data Analytics, Adaptation, Feedback Loops, AI Milestones	6	20.0%
Psychological Competency & Development	Competencies, SEL Standards, Behavioral Trends, Emotional Assessment Tools,		

Table 7 Interview Responses – Industry-Education Collaboration

Respondent N°	Interview Response	Keyword
1	I think joint ventures with tech firms help bring innovation into our curriculum.	Innovation
2	We sometimes struggle to align industry goals with our educational values.	Alignment
3	I appreciate how tech partners provide access to advanced AI infrastructure.	Infrastructure
4	We find it difficult to maintain long-term commitment from private companies.	Sustainability
5	I've noticed collaboration accelerates the practical application of theories.	Application
6	We need more clarity on shared responsibilities in these partnerships.	Role Definition
7	I value how collaboration boosts our digital literacy and capacity.	Capacity Building
8	We need ethical checks when industries are involved in student-centered tools.	Ethical Standards
9	I think co-developing tools makes the tech more relevant to our actual needs.	Relevance
10	We often face funding constraints that slow down joint innovation.	Funding
11	I've seen faculty resistance when tech dominates the counseling process.	Resistance
12	We collaborate for real-time feedback on pilot AI programs.	Feedback
13	I think students gain more career exposure when companies are part of the system.	Exposure
14	We face data ownership conflicts in cross-sector development projects.	Data Ownership
15	I believe joint development results in tools that reflect educational diversity.	Inclusivity
16	We lack policies that clearly regulate private-sector involvement.	Policy Gaps
17	I support partnerships that involve both pedagogical and technological voices.	Co-Design
18	We are learning how to manage shared timelines and priorities with tech firms.	Coordination
19	I feel industries push for speed while we value ethical deliberation.	Ethical Conflict
20	I believe collaborations must ensure student privacy is protected.	Privacy
21	We need evaluation benchmarks for tools developed collaboratively.	Evaluation
22	I like how partnerships introduce cutting-edge tools in the classroom.	Tools Introduction
23	We should increase training for educators on new AI platforms from companies.	Training
24	I support strategic alliances that lead to long-term innovation.	Strategic Alliance
25	We sometimes face issues in communicating between education and tech language.	Communication Gap
26	I think mentorship programs with companies strengthen student engagement.	Mentorship
27	We collaborate best when both sides have mutual respect and open dialogue.	Collaboration
28	We lack case studies and models for responsible AI collaboration.	Best Practices
29	I fear commercialization may override wellness priorities in some partnerships.	Commercialization
30	We've successfully piloted AI tools with industry support in our group sessions.	

Table 8 Thematic Analysis – Industry-Education Collaboration

Thematic Word	Grouped Keywords	Frequency	Percentage
Strategic Co-Development	Co-Design, Collaboration, Pilot Testing, Application, Feedback	5	16.7%
Ethical & Privacy Considerations	Ethical Conflict, Privacy, Ethical Standards, Commercialization, Data Ownership	5	16.7%
Institutional Barriers	Resistance, Policy Gaps, Communication Gap, Role Definition	4	13.3%
Infrastructure & Innovation	Tools Introduction, Infrastructure, Innovation, Strategic Alliance	4	13.3%
Educational Alignment	Alignment, Relevance, Inclusivity, Evaluation	4	13.3%
Professional Development	Training, Mentorship, Exposure	3	10.0%
Resource Constraints	Funding, Sustainability	2	6.7%
Governance & Regulation	Best Practices, Coordination	2	6.7%
Cultural Collaboration	Respect, Pedagogy-Technology Balance	1	3.3%

Table 9 Final Thematic Grouping into 5 Core Key Words

Core Key Word	Grouped Thematic Words	Frequency	Percentage
1. Ethical & Human-Centered Governance	Ethical Governance, Privacy & Data Ethics, Critical Reflection, Ethical & Privacy Considerations, Governance & Regulation	24	20.0%
2. Personalization & Psychological Development	Human-Centered Approach, Emotional & Behavioral Mapping, Psychological Competency & Development, Group & Peer Interaction, Professional Development	24	20.0%
3. AI Intelligence & Data Structuring	Semantic & Contextual Accuracy, AI Decision Support, Data Structuring & Intelligence, Algorithmic Fairness, Measurement & Evaluation, Data-Driven Adaptation	36	30.0%
4. Strategic Collaboration & Institutional Integration	Strategic Co-Development, Institutional Barriers, Educational Alignment, Educational Integration, Infrastructure & Innovation, Cultural Collaboration	22	18.3%
5. Goal-Oriented Counseling Models	Goal-Setting & Alignment, Resource Constraints, Cultural Sensitivity	14	11.7%
→ Total	—	120	100%

HAVING BREAST CANCER IN THE PANDEMIC: A QUALITATIVE STUDY ON A CASE

Oya Ögenler¹, Selda Okuyaz²

Abstract: Breast cancer is the most common and life-threatening cancer among women. Individual, socioeconomic and cultural characteristics, the society in which she lives, affect the woman's quality of life and health status during the cancer process. The ethical problems women experience due to breast cancer in ordinary times have become more complex with additional problems related to the COVID-19 pandemic. This study aims to raise awareness about the importance of the biopsychosocial approach in the physician-patient relationship through the experiences of a case diagnosed with breast cancer. Our study evaluated and compared the experiences and opinions of a 52-year-old woman diagnosed with invasive ductal breast cancer in the first six months of the epidemic with the literature. It is clear that breast cancer is closely linked to sexual identity, and "being a cancer patient" can be described as a life-changing crisis. The pandemic period has characteristics against the cancer patient due to restrictions. She stated that the patient diagnosed with cancer had positive characteristics, such as a physician-patient relationship and social determinants in the hospital-related processes, but she experienced social exclusion due to the pandemic period. As a result, it is clear that the biopsychosocial holistic view of the health personnel is as effective as the patient's individual characteristics and social determinants, the relationship between the patient and the health personnel, and the shaping of the treatment process.

Keywords: breast cancer, physician-patient relationship, COVID-19, ethical issues, quality of life

Cáncer de mama en la pandemia: un estudio cualitativo sobre un caso

Resumen: El cáncer de mama es el cáncer más común y potencialmente mortal en mujeres. Las características individuales, socioeconómicas y culturales, así como la sociedad en la que viven, afectan su calidad de vida y su estado de salud durante el proceso oncológico. Los problemas éticos que las mujeres experimentan debido al cáncer de mama en tiempos normales se han vuelto más complejos junto con los problemas adicionales relacionados con la pandemia de COVID-19. Este estudio tiene como objetivo concientizar sobre la importancia del enfoque biopsicosocial en la relación médico-paciente, a través de las experiencias de un caso diagnosticado con cáncer de mama. Nuestro estudio evaluó y comparó las experiencias y opiniones de una mujer de 52 años diagnosticada con cáncer de mama ductal invasivo durante los primeros seis meses de la epidemia con la literatura existente. Está claro que el cáncer de mama está estrechamente vinculado a la identidad sexual, y ser "paciente con cáncer" puede describirse como una crisis que cambia la vida. El período de la pandemia presenta características adversas para los pacientes con cáncer debido a las restricciones que se presentan. La paciente afirmó que tenía características positivas, como una buena relación médico-paciente y determinantes sociales en los procesos hospitalarios, pero experimentó exclusión social debido al período de la pandemia. Como resultado, es evidente que la visión holística biopsicosocial del personal sanitario es tan eficaz como las características individuales del paciente, los determinantes sociales, la relación entre el paciente y el personal sanitario y la configuración del proceso de tratamiento.

Palabras clave: cáncer de mama, relación médico-paciente, COVID-19, cuestiones éticas, calidad de vida

Tendo câncer de mama na pandemia: um estudo qualitativo de um caso

Resumo: Câncer de mama é o câncer mais comum e ameaçador à vida entre mulheres. Características individuais, sócio-econômicas e culturais e a sociedade na qual ela vive, afetam a qualidade de vida e o estado de saúde da mulher durante o processo do câncer. Os problemas éticos que as mulheres vivenciam devido ao câncer de mama em tempos normais, tornaram-se mais complexos com problemas adicionais relacionados à pandemia pelo COVID-19. Esse estudo objetiva aumentar a conscientização sobre a importância da abordagem biopsicosocial na relação médico-paciente, através das experiências de um caso diagnosticado com câncer de mama. Nosso estudo avaliou e comparou experiências e opiniões de uma mulher de 52 anos de idade diagnosticada com câncer de mama ductal invasivo nos primeiros seis meses da epidemia com a literatura. Está claro que câncer de mama está intimamente ligado a identidade sexual e "ser um paciente com câncer" pode ser descrito como uma crise que muda a vida. O período da pandemia tem características desfavoráveis para paciente com câncer devidos às restrições. Ela afirmou que a paciente diagnosticada com câncer tinha características positivas, tais como a relação médico-paciente e os determinantes sociais nos processos relacionados ao hospital, mas ela vivenciou exclusão social devido ao período da pandemia. Como resultado, está claro que a visão holística biopsicosocial do pessoal de saúde é tão eficaz quanto as características individuais do paciente e os determinantes sociais, a relação entre o paciente e o pessoal de saúde, e a definição do processo de tratamento.

Palavras chave: câncer de mama, relação médico-paciente, COVID-19, questões éticas, qualidade de vida

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Introduction

The coronavirus disease 2019 (COVID-19), identified in December 2019 in Wuhan, China, was declared a global epidemic by the World Health Organization (WHO) in early March 2020. As in many other countries, regulations have been made for health care services as of March 10, 2020, in Turkey(1). In this period, individuals with chronic health problems, including cancer patients, were more adversely affected than standard patients. The absence of cancer-specific emergency standards other than the standards of care for the COVID-19 pandemic, such as justice, the duty of care, the duty to protect resources, transparency, consistency, proportionality and accountability, caused the process to change against the individual with cancer. Restrictions on diagnosing and treating cancer diseases and elective surgeries can be classified as the most significant disadvantages during the pandemic(2). However, in ordinary times, cancer is a physical and psycho-social disease that includes many surgical processes, the excess of drugs used and their side effects, the possibility of metastasis, body image loss anxiety, economic, psychological, emotional, physical and environmental difficulties. There are differences in cancer rates according to gender. The impact of COVID-19 on cancer patients during the pandemic also differed by gender and age(2,3,4). Cancer treatment cannot be postponed for any event, as in oncology, studies show that patients with low immunity is more affected by the COVID-19 disease, affecting the mortality rate, is not considered safe enough to prevent treatment. The cancer patient is a member of a vulnerable group(2). In the COVID-19 pandemic, the magnitude of the effects of suspending screening programs for cancer patients, the closure of standard polyclinic examinations in the health system, and delays in cancer diagnosis and treatment on diagnosis and mortality rates cannot be estimated. While delays in diagnosis and barriers to transportation cause a decrease in incidence, barriers to access to cancer treatment and care are likely to cause an increase in advanced-stage diagnoses and cancer deaths(2,5,6).

Breast cancer, the most common among women, accounts for 25% of all female cancers worldwide(7). In general, the increase in cancer patients

worldwide and in Turkey can be attributed to living conditions such as unhealthy diet, alcohol and tobacco use. The estimated number of new cancer cases worldwide in 2020 is 19.3 million, with 233,834 in Turkey(3,7). Female breast cancer ranks first in new cancer cases, followed by lung, colorectal, prostate and stomach cancers. Cancer is one of the most important causes of death under the age of 70 in many countries, including Turkey(7).

Cancer is a chronic systemic disease(8). Being diagnosed with a chronic disease can turn the lives of patients and their families upside down. Everything from daily routines to family dynamics has to change to adapt to the new normal the disease brings. In addition to the economic and cultural difficulties in the chronic disease process, the possibilities and life expectancies of the patient are effective in coping with the difficulties. The disease, which disrupts the general functioning of the patient's environment, can lead to biopsychosocial problems, and the patient and her family may not know how to cope with difficulties during the process. Family members may face different emotional challenges depending on their relationship with the loved one who has the disease. The patient may feel grief or loss about her life and the future she imagined before her diagnosis. The family member who cares for the patient may sometimes feel overwhelmed and exhausted and experience compassion fatigue. The effect of the disease on the patient and her environment can be more complex and challenging due to the intensity of the side effects of the treatment process in cancer(9).

In addition, it can be thought that the fear of death of cancer patients and their relatives may differ from other times during the pandemic. The mentality of the health personnel who provide health care for cancer in the event of a pandemic or a possible disaster can determine the attitude and behavior of the cancer patient undergoing the diagnosis and treatment of cancer. Some recommendations draw an ethical framework for the treatment of individuals with cancer in resource-limited settings. Unfortunately, these inconsistent frameworks cannot be said to meet the required need(2). Very recently, an earthquake in Turkey affected 11 provinces and, indirectly, the whole country. The cancer patient underwent the process

in an intense period, except for her disease. Natural events, terrorism, and war will affect the cancer patient more than the normal individual.

For this reason, it is important to examine the sample cases reached in extraordinary periods to shape the diagnosis and treatment processes in favor of the patient. In this context, the views of a patient diagnosed with early-stage cancer during the pandemic period in 2020 were evaluated in comparison with the literature in terms of biopsychosociality. This study aims to guide the patient-healthcare worker relationship and raise awareness by evaluating the approach to the body and death of the patient diagnosed with cancer in extraordinary situations such as pandemics from a biopsychosocial perspective.

Case

Right breast-conserving surgery was performed on a 52-year-old single and nulliparous patient diagnosed with invasive cancer with a tru-cut biopsy in November 2020. Axillary node was negative, stage 1 right breast cancer (T1, N0, M0), HERS2-, and Ki-67<10 hormone receptors were positive. The patient, a healthcare worker, received four cycles of chemotherapy and 35 working days of radiotherapy after surgery. She was scheduled to take 1 mg of anastrozole for ten years. She is still being followed up by the general surgery and medical oncology departments every six months.

Discussion

The number of patients diagnosed with cancer through screening programs is increasing day by day. The difference of 75% between the number of patients diagnosed between 2008 and 2020 can be considered an indicator of the rate of increase(10) 30% of cancer diagnoses in women are breast cancer, and 15% of deaths are from breast cancer. However, with the help of cancer screening programs, early diagnosis and treatment opportunities have reduced the expected death rates from cancer(11). There are 331 Cancer Early Diagnosis, Screening and Education Centers (KETEM) in Turkey, at least one in each province(10). It is envisaged that women apply to KETEM or different cancer diagnosis centers at the secondary and tertiary levels in an organized manner. Breast

cancer is followed up with monthly breast self-examination and once-a-year mammography, recommended for all women between the ages of 40 and 69(12).

Our case had a regular ultrasound every six months for five years before diagnosis due to axillary lymphadenopathy, and had a mammogram once a year. When she applied to a different health institution two months later than usual, instead of the sixth month due to the pandemic, for the USG before the diagnosis, the radiologist who performed the USG stated that he saw a suspicious mass, but added that three months could be waited for the biopsy. Since the patient is a healthcare worker, it can be thought that she is less affected by this process, which works against the cancer patient. The fact that a woman tries so hard for early diagnosis of breast cancer with the thought that 'I can be sick at any moment' is a great haste to delay the disease and protect the body. According to this view, a woman should do everything she can, knowing it is her responsibility. The literature supports the efforts of our case for early diagnosis. Following the traditional sexist role, the woman passively and patiently strives for her body, which needs to be exhibited and protected, knowing that cancer can happen at any moment. For a woman who sees herself through someone else's eyes, protecting her health can be synonymous with protecting her body. From this point of view, a breast cancer diagnosis can be a tool for protecting the body, not a goal. The difference of the breast from other organs is that it is important in cosmetics and body image and is accepted that it represents gender. The female breast is in an important position for the woman in the visible part of the body, which has pleasant curves and enables the baby to integrate with the mother. According to the value given by society, the breast, which must be alive enough to defy gravity, is complemented by clothing and contributes to the sexual appearance of the woman(13,14). It is certain that the influence of society's health discourses on the formation of the thoughts of women with cancer, including our case.

Cancer treatment process

According to the WHO definition, health is not only physical but also mental and social well-be-

ing. Physiological and biological markers of the health of the patient diagnosed with breast cancer include imaging tests such as breast MRI, PET scan, blood biochemistry, immunological and histopathological diagnosis methods, and many procedures performed on the patient or tissue before and after surgery. It can be argued that the mental state of a woman diagnosed with breast cancer differs from that of other disease diagnoses(15,16).

The coordinated work of radiology, surgery, pathology, medical oncology and radiation oncology in cancer processes will shape the patient's future. Physicians need information about the woman's life expectancy, social and mental state, and body in terms of clarification and consent. The patient and her relatives are in the process psychologically, socio-culturally and economically. How long the treatment process will last, how much it will affect the patient and her environment, and possible negativities are critical situations that should be understood in detail by the patient and her environment.

The patient's emotional state, physical health, quality of life and treatment compliance will vary according to the approach of the physicians/health personnel. The woman's body image will change depending on the type of surgery determined by the general surgeon according to the stage and type of cancer. The woman's lived experiences, beliefs, and body perception, depending on the thoughts of others about her own body affect the psychological and physiological state in the post-operative period(17). The surgeon's clarification will prevent the patient's anxiety about her illness and body image. Even if the physician's knowledge and experience, as well as the patient's adequacy, do not eliminate the body image anxiety, it enables the patient to act by believing that the decision made is correct for the patient's future. The patient may not change the decision made by the physician, and the possibility of rejection may be very low, but the clarification of why the operation was performed in this way will enable the woman to say "the right decision" in the absence of beautiful curves while wearing her dress every day(18). The importance of realistic information given by the physician, allowing questions to the physician, and a confident and supportive healthcare professional cannot be denied.

Possible problems, side effects, and survival should be explained to the patient. However, as mentioned in one study, it is wrong to set a deadline for your life by a physician. Giving percentages of how much life is left causes people to become numbers. The surgeon of our case mentioned that the cancer was detected at an early stage, that the operation would be shaped according to the axillary metastasis during the operation, and that possible side effects were mentioned, but no explanation was given that the date of death would affect the prognosis. In case of complete closure during the pandemic, the procedures have been accelerated to perform the surgery as soon as possible. The physician's asking the patient what information she wants to learn will contribute to the patient's compliance. Confidence and compliance with treatment will increase when the patient receives information about the prognosis, similarly from all physicians participating in the process from the beginning of the disease(19). The chemotherapy process was followed by a medical oncologist in a different city instead of the patient's health institution. The possible percentages of metastases after treatment were mentioned in the clarification and consent of the medical oncologist. The chemotherapy drugs to be chosen, the purpose for which they are chosen and their contribution to the treatment of the patient are explained. The side effects of the drugs used in each chemotherapy cycle were explained to the patient in detail, and the possible side effects and the drugs to be used and the emergency numbers to call were given to the patient with a written document. The patient who had a throat infection during the second chemotherapy cycle stated that when she heard the sentence "do not be in the hospital, there is no place for you" from her physician friend in the city where she lived, she felt that she could die at that moment. The sentence "There is no room for you" is a cautionary example of how the restrictions affect the cancer patient's chances of survival, with no chance of being hospitalized with an illness other than COVID-19 during the pandemic. Cancer is associated with "death" in society. A study stated that healthcare professionals informed their patients about the prognosis based on mortality(19). In our case, there was no association with death in the clarification process. The healthcare professional friends outside the pa-

tient's immediate family associated the diagnosis with death and exposed her to social stigma/exclusion. In the literature, there is a need for a study on the views of healthcare professionals about the social exclusion/stigmatization of cancer patients or their relatives.

Being diagnosed with cancer, the presence of metastases, and how the treatment process will be shaped affect the patient and her family. Socio-economic opportunities, insurance availability, accessibility to the physician, and difficulties in understanding the terminology in the diagnosis and treatment of cancer necessitate mentioning the existence of a socio-cultural emotional dimension that is more intense and different from other diseases(16,20,21). In this context, the social determinants of health can be divided into five subgroups; individual (age and gender), socioeconomic (unemployment, working conditions, poverty and social exclusion), environmental (housing, social environment and clean food and water), lifestyle (physical activity, addiction and sexual preferences) and transportation (transport, social services, education). Our case stated that her characteristics are being over 50 years old and in menopause; socioeconomically, she has above-average economic power as an active health personnel and sufficient social support for the hospital process. However, she has experienced social exclusion due to the pandemic and her cancer. As environmental determinants, living in a house with clean water and positive features in terms of the environment; as lifestyle, she stated that she had a history of smoking for four years, did not have any addiction history and was not married. She added that since it was a pandemic period, a permit was obtained to be used in all restrictions for transportation and social services, and she used her means. Our case has positive characteristics in terms of social determinants that many women with breast cancer do not have. According to studies, the patient's quality of life and health are adversely affected by the negativity of social determinants. There are also studies showing that women have worse health status in terms of social determinants(20). The health status of economically weak people is defined as worse. It is important for our case to be in good financial condition, have easy access to hospital facilities from a social point of view,

and be able to meet her health-related needs with her means, especially in a period when chronic patients are having problems, such as during the pandemic period. However, it is important, mentally and socially, that she states that she is deprived of the communication network provided by others as social support, which makes the individual feel cared for and loved, and that she is experiencing social exclusion(20). Breast cancer is a disease directly related to the sexual identity of women. Our patient stated that she could not tell non-health individuals she had breast cancer because the word "breast" had sexual connotations.

With the cancer diagnosis, the person has encountered a traumatic event that threatens her existence and changes her normal life, making her think she will die. Being diagnosed with cancer is a situation suitable for the definition of "crisis"(16). If we or someone close to us is experiencing a loss, a unique experience occurs, respectively, which is overwhelming and confusing; it is suggested that during this period, the patient will experience five phases of emotions, such as denial, anger, bargaining, depression and acceptance, according to Kubler-Ross classification(22). At the same time, the patient, who is in a physically, psychologically, socially, economically challenging period for diagnosis and treatment, experiences a period of "crisis" regarding her health(15). Studies are showing that the psychological state of women diagnosed with cancer affects the acceptance of the disease and compliance with the treatment process. The abilities and experiences of the patient diagnosed with cancer will affect her coping with the crisis(16). The insidiousness and fatality of cancer, the changes in the body during the treatment process, and the process of becoming ugly and in need of care provide the emotional definition of the process. According to the literature, women with cancer who experience anxiety after diagnosis experience more distress, anxiety and depression than men(16,21). Since our case is a health worker, it can be argued that the level of knowledge on cancer and death contributes to the excellent management of the process, and as a health worker, the physician-patient relationship is different from non-health patients. The positive features of the patient's treatment compliance process may have reduced the discomfort caused by the treatment.

The patient with a cancer diagnosis requires a medical understanding beyond the standard medical approach, with good communication skills and far from stereotypical thoughts, more than the patient diagnosed with any disease. Communication between the physician and the patient will create trust and ensure that the patient's health is positively affected(23). As seen in our case, the positive effect of the physician-patient relationship is obvious. Attitudes and behaviors of patients, physicians and their environment towards "goodness" shape the disease process of women with breast cancer(20).

Conclusion

It is important to ensure the institutional structure that will ensure the continuity of the approach in the diagnosis and treatment process in the ordinary period so that the patient does not suffer from inequality due to restrictions during the pandemic. The case stated that although she was a healthcare worker, she was affected by limitations and social exclusion. It should be considered that cancer is a disease that is affected more by social

determinants than other diseases for each period. For this reason, it is important to determine the presence of the patient's biological markers and other factors and to support them with social institutions for the disease process to be positive, increase the quality of life, and be healthier. It is important to inform the diagnosed patient and their family about what will happen during the disease process, including biological, psychological, and social factors.

The biopsychosocial approach to the cancer patient will affect the entire treatment process from diagnosis. Since cancer is a disease that requires multidisciplinary work in the diagnosis and treatment process, opening multidisciplinary areas that will ensure this unity in hospitals, providing physicians and all healthcare professionals with the necessary training to provide the biopsychosocial approach necessary for cancer patients, to reveal the positive and negative attitudes and behaviors that will affect the patient-physician relationship administratively and to provide the necessary initiatives to reinforce the positive features and eliminate the negative features are important.

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WORLD HEALTH ORGANIZATION***From loneliness to social connection - charting a path to healthier societies: report of the WHO Commission on Social Connection.***

Geneva: World Health Organization; 2025. Licence: CC BY-NC-SA 3.0 IGO. ISBN 978-92-4-011236-0 (electronic version) ISBN 978-92-4-011237-7 (print version)

Fernando Lolas Stepke¹

El concepto de “salud social” es, como dice este reciente informe de OMS, el “tercer pilar” del concepto de “salud” propugnado por esa organización, cuya clásica definición indica que salud es un completo estado de bienestar físico, mental, espiritual y social y no solamente la ausencia de enfermedad.

Aunque esta definición es utópica, pues nunca existe completo bienestar y las personas “sanas” o “normales” viven en realidad en una zona “neutral”, con estados variables de bienestar y malestar, lo importante es el desglose analítico de esta nueva propuesta. La mayoría de las definiciones de salud se refiere a individuos y por ello su expansión a áreas tales como *salud global*, *salud pública* y *salud internacional* encuentra dificultades para dar cuenta de los “determinantes relacionales” del estado de bienestar. Estos no siempre son controlables por los individuos, porque dependen de interacciones con otras personas. No siempre las expectativas individuales encuentran eco en el comportamiento de éstas, como se evidencia en el discurso sobre derechos que carece por completo de significado o concreción real si otras personas no sienten como deber respetarlos. Un derecho subjetivo, aunque se manifieste en códigos escritos, es siempre necesidad o deseo legitimados en un contexto específico y su frecuente desconocimiento o violación dependen de los contextos en que se proclaman. La influencia de la cultura y las determinaciones económicas o políticas explican que lo que es derecho en algunas partes del mundo o para algunos grupos no sea plenamente reconocido o aceptado universalmente.

Autonomía, individualidad y conexión son indisociables de la vida contemporánea. Difíciles de articular armoniosamente en la vida cotidiana, porque existen “estilos individuales” codificados bajo el término técnico “personalidad”, que alude a la construcción individual de los hábitos y a preferencias que se manifiestan en muchos ámbitos vitales. Conocido es que tales características individuales predisponen a algunas personas a trabajar y vivir mejor rodeadas de otras personas, y a otras a preferir el aislamiento. Incluso, hay variaciones circadianas en la forma que cada individuo responde a las sollicitaciones de la vida social e incluso a los efectos de algunos estimulantes. La cafeína puede mejorar el rendimiento intelectual en algunos, pero puede reducirlo en otros.

La diversidad humana es una constante que necesariamente debe ignorarse cuando se planean intervenciones societarias o se formulan políticas públicas. La acción de los psicofármacos depende no solamente de las expectativas que se pongan en ellos sino también de características de los sistemas nerviosos. Ivan Petrovich Pavlov pudo distinguir entre perros con sistema nervioso fuerte y perros con sistema nervioso débil cuando comprobó que no todos reaccionaban igual ante situaciones estresantes. Muchas generalizaciones basadas en estereotipos prueban ser incorrectas, como aquellas que se refieren a grupos etarios. Precisamente, en la ancianidad (como nos recuerda Jonathan Swift en su sátira sobre los Struldbruggs) es cuando más difieren entre sí las personas, de modo que hablar de “la tercera edad” como un grupo homogéneo entraña desconocer que la diversidad humana es la regla. Debiera tenerse

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en cuenta en generalizaciones sobre el efecto de las intervenciones sobre la salud y el sistema nervioso antes de declarar precipitadamente que algunas son beneficiosas y otras deletéreas. Tal vez esto constituya una buena base para reflexionar sobre el futuro de las máquinas humanoides y sin duda tiene implicaciones cuando se trata con especies no humanas. Los animales también tienen “personalidad” (el clásico libro de Munro Fox lleva ese título).

Tres conclusiones cruciales emanan de este informe. La primera es que la soledad no deseada, entendida como aislamiento y falta de contactos de apoyo en situaciones de emergencia, tiene consecuencias negativas y afecta al bienestar de las personas.

La segunda es que impacta en la salud percibida y en la salud objetiva de las personas de modo negativo, incrementando la morbilidad y la mortalidad.

La tercera es que la acción mancomunada de los expertos y las personas que toman decisiones en salud pública puede contribuir a diseñar intervenciones que propicien la conexión social.

La existencia de ministerios de la soledad, como los existentes en Gran Bretaña y Japón, indica la importancia que se ha dado al problema de la falta de conexión social. Sin embargo, cabe recordar que las intervenciones deben ser adecuadas al contexto social y científico en que se implementen. No todas las conexiones sociales son positivas. Algunas pueden no ser beneficiosas. Las personas, por su diversidad, pueden preferir algunas y rechazar otras.

Hay que distinguir, por tanto, entre los sentimientos subjetivos de soledad que pueden experimentarse incluso en una multitud y el aislamiento no deseado, producto de limitaciones físicas, vejez o enfermedad (*La multitud silenciosa*, de Riesman y colaboradores, puso este tema en boga en los años 50 del siglo XX, aunque el título no responde exactamente a la intención de los autores). Cualquier intervención debe estar precedida por un análisis sociológico del tipo de comunidad al que se pertenece, pues en algunas culturas priman cánones de sociabilidad que no pueden generalizarse. Cuando se habló de “sociedades enfermas” (Halliday) todo el mundo académico entendió que se trataba de una metáfora, porque la sociedad no es un “sujeto” que pueda enfermar. No obstante ello, puede emplearse esta expresión para situaciones de anomia generalizada, caos destructivo y prevalencia incrementada de dolencias personales.

Este informe, profusamente ilustrado con datos y estudios, es sin duda un valioso aporte a la comprensión de estos fenómenos —aislamiento, soledad, conexión social—, a su estimación cuantitativa y su evaluación cualitativa, y a sus implicaciones sanitarias. Es un significativo impulso a desarrollar mediciones adecuadas y a estimar la patogenicidad de prácticas sociales tan extendidas, como el uso de plataformas digitales, el teletrabajo, la telemedicina, la automatización de los procesos económicos, el adoctrinamiento político y la influencia omnipresente de las persuasiones ocultas de la publicidad y la propaganda.

LA DIMENSIÓN MORAL Y SOCIAL DE LA PSIQUIATRÍA

KALLIVAYALIL, R.A., GOGINENI, R.R., AKHTAR, S. (editores)

The Glow of Synthesis. Twelve Beacons of Light in Social Psychiatry.

Jaypee Brothers Medical Publishers: New Delhi & London, 2025 (203 págs)

ISBN 978-93-6616-364-2

Fernando Lolas Stepke¹

Este libro recoge ensayos sobre doce personas cuyas contribuciones se juzgan importante para relevar la dimensión social de la psiquiatría y la salud mental. Salvo Norman Sartorius, aún activo, los demás son figuras históricas: Karen Horney, Erich Fromm, Erik Erikson, Geza Roheim, Margaret Mead, Emile Durkheim, Theodor W. Adorno, Joshua Bierer, George Morrison Carstairs, Ravi L. Kapur, Julian Leff.

Junto a una breve biografía, los textos destacan sus contribuciones a la antropología, la sociología, la crítica cultural, la psicología y la psiquiatría. Sin dudar de lo acertado de la elección de estos nombres, obviamente habría otros que podría haberse incluido.

El volumen se completa con un apéndice que resume vida y obra de otros pioneros, entre los cuales cabe mencionar a Juan Marconi, de Chile, Javier Mariátegui, de Perú, Julio Arboleda-Florez, de Colombia, por nombrar algunos latinoamericanos, además de figuras relevantes de Grecia, Reino Unido, India, Bulgaria, Australia, Japón y Alemania.

La primera conclusión que se impone tras la lectura de este volumen es que todos los biografiados fueron, de una forma u otra, moralistas. Esta vieja palabra resume la preocupación por las complejidades e incertidumbres de la vida humana en sociedad. También es destacable que en todos ellos la preocupación por la cultura como expresión de lo social fue determinante para destacar su influencia en las ciencias de la salud, el bienestar y la calidad de la vida. Cómo han sido recibidos y valorados sus aportes es tema de controversia. En la sección dedicada a “Psicoanalistas culturalmente inclinados” sorprende que los tres biografiados, Horney, Fromm y Erikson, de alguna manera se opusieron a las opiniones de Sigmund Freud, el “biólogo de la mente”, cuyas reflexiones culturales y antropológicas fueron producto de opiniones personales o evidencias incompletas. Sorprende también la azarosa vida de esas personas, incluyendo la notable biografía de Erikson, quien nunca conoció a su padre, o las resistencias que encontró Fromm para divulgar sus ideas a pesar de ser un polígrafo popular.

Las contribuciones de sociólogos y antropólogos (Roheim, Mead, Durkheim, Adorno) ilustran la fertilidad de disciplinas no médicas para la fundación de una “psiquiatría social”. Sorprende saber que la clásica obra de Durkheim sobre el suicidio no concitó mayor interés cuando fue publicada y que las aportaciones sobre estudios culturales de Roheim y Mead han sido parcialmente aceptadas por la comunidad psiquiátrica, probablemente por las barreras que imponen los lenguajes exclusivos y excluyentes de la especialización disciplinaria.

Ya en la sección sobre psiquiatras que hicieron de la dimensión social el eje central de sus preocupaciones se llega a observaciones de valor práctico. Joshua Bierer, fundador de la World Federation for Mental Health, tiene hoy valor institucional y conceptual. Castairs, Kapur, Leff y Sartorius han abogado, con mayor o menor fortuna, por ampliar horizontes en la práctica de la psiquiatría y en sus dimensiones epidemiológicas. Tal vez recordar la obra de Franco Basaglia no hubiera estado demás,

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como asimismo dedicar un estudio a otras personas que hicieron contribuciones a la labor comunitaria, la desinstitucionalización y la lucha contra el estigma asociado al trastorno mental, pero ello se repara en parte con las breves biografías incluidas en el Apéndice.

Es un volumen de gran valor porque toda consideración social es al mismo tiempo una reflexión moral y el trabajo de quienes están representados en este volumen puede considerarse desde varias perspectivas. Todas ellas complementarias del paradigma dominante de la psiquiatría médica tradicional, con su énfasis en los sustratos neurofisiológicos y bioquímicos del psiquismo, que recuerdan disputas ya superadas en la psiquiatría contemporánea.

MARTÍNEZ GÓMEZ, JESÚS ARMANDO y CABRERA-CABRERA, ANTONIO MARÍA (Coordinadores)

Bioética global y su impacto en el siglo XXI.

Ciudad de México: Tirant Humanidades, 2025. ISBN 978-84-1183-842-9, 478 pp.

Alberto García Gómez¹

En el contexto actual de crisis ecológica, desigualdad social y transformaciones tecnocientíficas aceleradas, el libro *Bioética global y su impacto en el siglo XXI* constituye una aportación coral y plural al pensamiento bioético contemporáneo. Coordinada por Jesús Armando Martínez Gómez y Antonio María Cabrera-Cabrera, esta obra colectiva reúne a más de veinte autores iberoamericanos que reflexionan sobre los fundamentos, desafíos y aplicaciones de la bioética global, desde perspectivas filosóficas, teológicas, jurídicas, sociales y científicas.

El volumen se organiza en cuatro partes que articulan un recorrido desde los fundamentos teóricos de la bioética hasta su aplicación práctica en contextos globales y tecnológicos.

La primera parte, “Introducción a la bioética global y sus fundamentos”, expone los marcos conceptuales y metodológicos que permiten comprender la transición de la bioética clínica a una bioética global. En el capítulo inaugural, Martínez Gómez y Gemma Fernández Pichardo reconstruyen la evolución de los principios de autonomía y responsabilidad, mostrando cómo la ética del respeto a la persona se amplía hacia la responsabilidad solidaria con toda forma de vida. Roberto Yenny García aborda el diálogo entre la bioética teológica y la bioética secular como condición para una ética global inclusiva, mientras Fernando Lolas Stepke examina el desarrollo de una “mentalidad bioética” en Iberoamérica. María Elizabeth de los Ríos Uriarte propone los principios de solidaridad, socialidad y subsidiariedad como claves para afrontar los desafíos del siglo XXI, y René Zamora Marín rescata el pensamiento ético cubano (Varela, Luz y Caballero, Martí) como expresión local de principios universales.

La segunda parte, “La bioética en el contexto contemporáneo”, integra contribuciones que examinan los aprendizajes éticos del COVID-19 (Miguel Kottow), la gestión global de recursos sanitarios (Patricia Mancilla Dávila), la bioética “en salida” hacia las periferias (Cabrera-Cabrera, Sánchez-Guerrero y Cerdio-Domínguez) y el pluralismo cultural (Eduardo Farías Trujillo). También destacan los análisis de Víctor M. Castaño sobre la dimensión institucional de la bioética y de Maldonado-Castellanos y Aguilar Navarrete sobre la “bioética ciudadana”, que amplía la deliberación ética a la participación social.

La tercera parte, “Ética aplicada a problemas globales”, desplaza el foco hacia los ámbitos socioambientales, comunitarios y biomédicos. Se abordan la relación entre pensamiento radical y diálogo bioético (Cerdio y Sánchez-Guerrero), la crítica a los imaginarios de la sostenibilidad neoliberal (Luna Nemeio), las terapias acuáticas y el derecho a la salud (Marccone Dapelo), la educación en derechos humanos en carreras de salud (Porras Araneda), los trasplantes faciales (Palomares Cantero) y la ética del cuidado en personas mayores (Mariscal Ureta, Pérez González y Keferstein).

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Finalmente, la cuarta parte, “Reflexión ética frente al desarrollo tecnológico”, plantea los retos que imponen la ciencia y la técnica contemporáneas. Ian Henríquez examina la relación entre *tékhnē, epistēmē* y regulación jurídica, y José Ramón Amor Pan cierra el volumen con una lúcida reflexión sobre “Verdad, belleza y bondad en la era de la inteligencia artificial”, donde propone una “bioética de la resistencia” frente a la fragmentación de la gobernanza tecnológica global.

La obra se distingue por su amplitud temática y pluralidad metodológica, conjugando enfoques filosóficos, teológicos, jurídicos y científicos. El hilo conductor es la noción de bioética global como horizonte integrador que supera los límites de la bioética clínica y busca responder a los desafíos planetarios de justicia, sostenibilidad y dignidad humana. Un aporte relevante es la relectura de los principios bioéticos —autonomía, beneficencia, no maleficencia y justicia— a la luz de categorías como responsabilidad, solidaridad y subsidiariedad, en continuidad con la Declaración Universal sobre Bioética y Derechos Humanos de la UNESCO (2005). Esta ampliación conceptual abre el camino hacia una ética pública global, en la que la responsabilidad individual se articula con la corresponsabilidad institucional y social.

También resulta significativa la integración de perspectivas latinoamericanas, tanto en la recuperación de tradiciones éticas locales (el pensamiento de Varela y Martí, por ejemplo) como en la atención a las desigualdades estructurales, la exclusión sanitaria y la pobreza ambiental. De este modo, el libro evita la homogeneización del discurso bioético y promueve un diálogo intercultural fecundo.

El volumen, por su extensión y diversidad, ofrece un panorama completo del estado actual de la bioética global, aunque su carácter misceláneo puede dificultar una lectura sistemática. Algunos capítulos se orientan más a la exposición histórico-conceptual, mientras otros desarrollan análisis aplicados con distinto nivel de profundidad. No obstante, la coherencia temática se mantiene gracias al propósito común de situar la bioética como “puente hacia el futuro” —en la expresión de Potter—, entre ciencia, ética y humanidad.

Destaca especialmente el equilibrio entre rigor académico y compromiso social, rasgo que otorga al libro una relevancia especial en el debate iberoamericano. Frente a la tecnocratización de la ética o la abstracción filosófica, los autores insisten en una bioética encarnada en la vida concreta de los pueblos y en los desafíos ecológicos y tecnológicos del siglo XXI.

Bioética global y su impacto en el siglo XXI es una obra de referencia para investigadores, docentes y profesionales interesados en los vínculos entre ética, ciencia, salud, medio ambiente y justicia global. Su enfoque interdisciplinario y su vocación de diálogo hacen de ella una contribución significativa a la consolidación de una bioética iberoamericana con proyección mundial, fiel a los principios de responsabilidad, solidaridad y respeto por la vida en todas sus formas.

Constituye, en suma, un esfuerzo colectivo por pensar la bioética desde el sur global, con mirada crítica, compromiso social y apertura intercultural. Por ello, su publicación por Tirant Humanidades representa un paso importante en la maduración académica del pensamiento bioético en lengua española y una invitación a seguir construyendo una bioética verdaderamente global, dialogante y humanizadora.

DECÁLOGO ÉTICO PARA LAS TECNOLOGÍAS EN SALUD

MARTÍN URRIALDE, J.A. (Coordinador)***Decálogo ético para la humanización y el uso de tecnologías en salud.***

CEU Ediciones, Madrid (España), 2025. (ISBN: 979-13-87860-04-02), 112 págs.

Jesús Armando Martínez Gómez¹

La irrupción de las tecnologías digitales en la medicina y la atención de salud ofrece enormes posibilidades para mejorar el acceso a los servicios sanitarios y elevar la calidad y corrección del diagnóstico, los procesos terapéuticos, la prevención y la rehabilitación de enfermedades, pero también genera incertidumbres y riesgos que hoy son objeto de análisis en numerosas publicaciones que persiguen delinear los elementos esenciales de un marco ético y jurídico apropiado para su regulación. La obra *Decálogo ético para la humanización y el uso de tecnologías en salud*, coordinada por el Dr. José Antonio Martín Urrialde, es el resultado de una reflexión profunda que busca equilibrar las posibilidades inquestionables que brinda la aplicación de las tecnologías digitales en el sector salud con el imperativo de preservar los valores humanos que son intrínsecos a la práctica médica.

Con prólogos de Emiliano Blasco Doñamayor y Julio Zarco Rodríguez, cada uno de los diez capítulos de esta obra colectiva constituye un tópico imprescindible para el análisis en profundidad de la problemática que aborda: 1. “Bienestar integral y salud digital” (Antonio Piñas Mesa), 2. “La educación de la ciudadanía y de los profesionales” (José Luis Bimbela Pedrola), 3. “Los peligros de la tecnología sanitaria ante la pérdida de los valores humanísticos” (José Antonio Martín Urrialde), 4. “Inclusión y no discriminación” (Benjamín Herreros), 5. “Telemedicina para accesibilidad: un pilar en la humanización de las tecnologías sanitarias” (Carlos Royo Sánchez), 6. “Tecnologías y medicina centrada en la persona” (Fernando Lolas Stepke), 7. “Seguridad y confidencialidad de los datos en tecnologías sanitarias: un pilar clave en la humanización” (Carlos Royo Sánchez), 8. “Interoperabilidad y eficiencia” (Carlos Gallego Pérez), 9. “Formación integral de profesionales” (Tomás Chivato Pérez), 10. “Mecanismos de evaluación para medir el impacto de las tecnologías en la humanización de la atención sociosanitaria” (José Antonio Martín Urrialde).

Fiel a su estructura y lógica, el texto comienza analizando la estrategia mundial de la OMS para el fortalecimiento de los sistemas de salud mediante la aplicación de tecnologías de salud digital como medio para hacer realidad la aspiración de salud para todos, alertando sobre los peligros de la medicina de perfección. A continuación se adentra en las dimensiones del concepto de salud desde una perspectiva integradora, que incluye cinco dimensiones esenciales (ética, física, emocional, social y espiritual), las cuales deberán ser atendidas para lograr preservar el carácter humanista de la praxis médica en la era tecnológica actual, que demanda un modelo médico centrado en la persona, en la integración de la IA con la supervisión humana y criterios de justicia que permitan una mayor inclusión y equidad en la distribución de los recursos de salud y las prestaciones médicas, que se podrían ver favorecidas por el uso adecuado de la telemedicina.

Desde la concepción de la medicina como saber orientado a la praxis (praxis tecnológica), que se encuentra en la interfaz entre ética, política y tecnología, se hace un llamado a centrar la atención médica en la persona —verdadero fin y no medio del desarrollo tecnológico—, para ayudarla a promover su

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bienestar, sanación y curación, previniendo para que este fin no se vea obstaculizado por la medicina del deseo. Se alerta sobre la necesidad de fortalecer la seguridad informática como vía para la protección de los datos, la privacidad y la información relativa al estado de salud y enfermedad de los usuarios de los servicios de salud, y se proponen directrices éticas para el logro de una interoperabilidad que propicie el mejor uso y eficacia de la información disponible. En sus capítulos finales, los autores se detienen en el análisis de la educación médica y en la necesidad de preservar su sentido humanista a través de un modelo formativo centrado en la persona y su dignidad, en la integración de las competencias clínicas con la formación en valores para el desarrollo de actitudes humanitarias en los profesionales de la salud, así como en la implementación de técnicas que permitan la evaluación cuantitativa y cualitativa del impacto de la tecnología digital en la humanización de la atención médica.

Aunque los temas son tratados con profundidad y gran rigor científico, la obra no se dirige sólo al público especializado. Sus autores apuestan por un humanismo digital participativo como sustento del desarrollo tecnológico de la medicina, “donde máquina y humano, tecnología y humanismo se den la mano de una manera armónica, integral e interdisciplinar”.

No cabe duda de que se trata de un manual de referencia que ofrece una guía ética de gran valor para orientar la labor de investigadores, médicos, profesores, responsables de políticas públicas y legisladores, a partir de sólidos referentes morales. Constituye, además, un texto de obligada consulta para quienes aspiran a seguir construyendo una medicina centrada en el ser humano y su dignidad, en el marco del dinámico y complejo contexto tecnológico en el que se desarrolla la práctica médica del siglo XXI.

NEUROCIENCIAS Y DERECHO

MARTÍNEZ GÓMEZ, JESÚS ARMANDO y PÉREZ GONZÁLEZ, EDGAR (Coordinadores)

Neurociencias, Inteligencia Artificial, Ética y Derecho

Editorial Tirant humanidades, 2025

Antonio Muñoz Torres¹

El libro reúne una serie de aportes interdisciplinarios que combinan temas como tecnologías emergentes, inteligencia artificial, neurociencias, ética, bioética, filosofía del Derecho y Derecho, con la intención de analizar críticamente cómo los avances tecnológicos y científicos están transformando nuestra percepción y concepción de la persona, la libertad, la responsabilidad, la democracia, los derechos humanos y la vida social.

Se plantea una reflexión principal: no estamos ante una mera “tecnología adicional”, sino ante transformaciones que alcanzan cimientos de nuestra vida individual y colectiva, por ejemplo, el concepto de “persona”, la percepción de la realidad, la valoración moral, la cognición, las nuevas formas de interacción, la salud mental, la justicia, etc.

El libro se compone de diez secciones con los siguientes ejes temáticos:

- Fundamentos de la Inteligencia Artificial IA
- Incidencia de las neurociencias, neurotecnologías e inteligencia artificial en la ética y la bioética.
- La interpretación de la libertad humana y de la inteligencia humana, especialmente frente a instrumentos tecnológicos que modifican o amplían nuestras capacidades.
- La mejora humana, el transhumanismo o las implicaciones de “mejora” (mejora cognitiva, física, neurológica) como desafío ético-jurídico.
- El funcionamiento de la democracia, la veracidad de la información, la participación política, en un contexto tecnológico donde la IA y las neurotecnologías interaccionan.
- Salud mental, prevención del suicidio, vulnerabilidad de ciertos sectores poblacionales, neurodiversidad.
- Justicia penal, seguridad ciudadana, ámbito fiscal: la penetración de tecnologías en estos campos y sus implicaciones normativas.
- Investigación científica, protección y redefinición del contenido de los derechos humanos, es decir, ¿cómo los derechos humanos se transforman o deben transformarse frente a estas nuevas tecnologías?
- Educación en el siglo XXI: cómo la neurociencia, la IA y las tecnologías emergentes afectan los procesos educativos, aprendizaje, docencia y quizá la construcción del conocimiento (mencionado en la sinopsis).

Las aportaciones clave de esta obra son, por una parte, la interdisciplinariedad, que destaca por cruzar las barreras entre Derecho, ética, filosofía, ciencias cognitivas y tecnología, enfoque necesario pues

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estas cuestiones requieren ser abordadas desde la óptica de más de una disciplina. Por otra parte, la perspectiva humana-centrada en la persona. Aunque la tecnología emergente es el motor del análisis, el libro hace un llamado a colocar «la persona», «la dignidad humana» y «el bien común» como ejes normativos.

Otro aporte importante es el relacionado con el marco normativo y ético revisitado: No basta con aplicar marcos jurídicos existentes (la obra sugiere que debemos repensar, renovar marcos éticos y jurídicos para afrontar los retos de tecnologías disruptivas, neurotecnologías, IA, etc. En el campo de los derechos humanos, se hace un llamado al reconocimiento de vulnerabilidades y de la transformación social: el libro no solo se queda en lo tecnológico o lo jurídico abstracto, también aborda ámbitos concretos, como salud mental, neurodiversidad, vulnerabilidad de ciertos sectores, lo que aporta un matiz más social y humano. Finalmente, pero no menos importante, se percibe que los autores consideran que estos cambios no están “en un futuro lejano” sino que ya están afectando nuestra vida social, jurídica, personal, y requieren respuestas ya (consciencia de la urgencia).

Neurociencias, Inteligencia Artificial, Ética y Derecho hace un llamado al estudio de realidades novedosas y complejas, como los campos de neurociencias y neurotecnología, junto con IA, que evolucionan vertiginosamente. Una obra como esta se enfrenta al reto de mantenerse actual y vigente frente a tecnologías que cambian aceleradamente y suscitan nuevas preguntas en diferentes áreas de la sociedad y el saber humanos. Por otra parte, al juntar muchas disciplinas (pluralidad de voces), pueden surgir tensiones metodológicas (por ejemplo, entre filosofía y Derecho, o entre ciencia y ética). Eso es un riesgo pero también una fortaleza: los problemas complejos requieren de una comprensión profunda. Asimismo, se pretende dar un paso hacia la aplicabilidad práctica, donde las reflexiones éticas y teóricas son adecuadas, pero el salto hacia políticas públicas, regulaciones o implementaciones concretas es siempre complejo. La obra invita a ese salto, pero dicho salto es un desafío. Finalmente, al tratar muchos temas, existe el riesgo de que cada tema se trate de manera más superficial que si se hubiera hecho una obra monográfica. Pero ello también convierte al libro en una panorámica valiosa.

El libro va dirigido a un público diverso, investigadores y académicos en Derecho, ética, filosofía del Derecho, ciencias cognitivas, neurociencias, tecnologías disruptivas, política, así como a profesionales de la justicia, reguladores, responsables de políticas públicas que se ocupan de tecnología, salud, educación, derechos humanos y también estudiantes avanzados que buscan comprender la intersección entre tecnología emergente (IA), ética, Derecho y neurociencias. Finalmente a interesados en la reflexión sobre cómo la IA y las neurotecnologías cambian la sociedad, los derechos humanos y la persona.

Dado que vivimos ya en plena era de la IA, donde la neurotecnología empieza a introducir nuevos modos de influencia sobre el pensamiento, la percepción y la conducta, este libro aparece en un momento oportuno. Plantea preguntas fundamentales: ¿qué significa ser libre en un mundo de algoritmos y neurotecnología? ¿Qué ocurre con la responsabilidad cuando las decisiones —o al menos los apoyos a las decisiones— pasan por sistemas cognitivos ampliados o híbridos? ¿Cómo proteger la dignidad humana cuando la tecnología puede intervenir directamente en los procesos neurocognitivos?

En resumen, *Neurociencias, Inteligencia Artificial, Ética y Derecho* es una obra que se atreve a mirar los cruces más inquietantes entre la tecnología avanzada y la vida humana desde un enfoque riguroso e interdisciplinario. No es únicamente un análisis técnico ni jurídico: es una invitación a la reflexión sobre qué tipo de futuro queremos, cómo las estructuras jurídicas y éticas deben adaptarse y cómo se debe proteger lo que nos hace humanos frente al avance tecnológico.

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DIRECTRICES ANTICIPADAS Y PLANIFICACIÓN ANTICIPADA DE LOS CUIDADOS. UNA TAREA PARA ALGORITMOS PREDICTIVOS

Fernando Lolas Stepke¹

En discusiones sobre legislación relativa a las disposiciones que las personas desean ver implementadas para situaciones de peligro vital el acento recae en eufemismos como “muerte digna” o “muerte médicamente asistida”. El público en general suele hablar de leyes sobre eutanasia, despenalización de las acciones médicas que aceleren la muerte, autonomía de las personas para decidir sobre los cuidados que aceptarían y otras materias.

Especial atención merecen las **directrices anticipadas** (*advance directives*) o “testamentos vitales”, expresiones de deseos que se manifiestan antes de las situaciones críticas del final de la vida. Pueden ser documentos oficiales, certificaciones o expresiones a allegados, que pueden sufrir revocación o modificaciones según las circunstancias. El origen de los “*living wills*” (testamentos o voluntades anticipadas) puede rastrearse hasta los años sesenta del siglo pasado y la primera concreción jurídica fue en California, Estados Unidos, asociada a las discusiones provocadas por los casos de Karen Quinlan, Nancy Cruzan y Terry Schiavo.

Las voluntades anticipadas están sujetas a varios supuestos. Primero, que la persona que las formula esté en condiciones de hacerlo desde el punto de vista de su capacidad o competencia cognitiva. Segundo, que pueda ser objeto de revisión a lo largo de la vida, ya que las actitudes y creencias pueden cambiar. Tercero, que las personas o sus allegados puedan representarse más o menos coherentemente el escenario en el cual debieran aplicarse. Finalmente, que su existencia sea conocida por las instituciones sanitarias o personas en condiciones de representar fielmente los deseos de quienes formulan tales deseos o preferencias. Ocurre a veces que familiares o amistades intervienen en momentos cruciales, a veces contradiciendo lo expresado con anterioridad, lo que pesa sobre las decisiones del personal sanitario. En el ámbito público, motivos religiosos o ideológicos tienen importancia para la discusión.

La idea de una **planificación anticipada de los cuidados** (*advance care planning*) es más inclusiva que la de directrices anticipadas. Se trata de procesos en los cuales las personas pueden manifestar, en conjunto con sus otros significativos y el personal sanitario, sus preferencias sobre cómo desearían ser tratadas aun en casos en que no exista posibilidad de muerte sino, por ejemplo, de incapacidad por demencia o enfermedades mentales graves.

Los dilemas éticos planteados por estas alternativas no solamente se refieren a la autonomía de las personas. Aparte de la adecuada evaluación de capacidades cognitivas, es necesario considerar el significado y el sentido de la vida individual en su contexto cultural, social y económico. Hay quienes sugieren que cuidados paliativos eficaces harían innecesario regular la forma en que se desee afrontar la muerte física y la muerte social. Se podría argumentar que las preferencias que se manifiestan con anticipación no reflejan la realidad de una contingencia inesperada y que la persona cambia a lo largo de la vida, de modo que no es la misma cuando se enfrenta a trances o situaciones imprevisibles. El factor esperanza no debe ser desestimado, como tampoco la noción arraigada en los profesionales sanitarios de que toda muerte o discapacidad permanente son fallas personales o del sistema sanitario y deben ser combatidas.

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La **autonomía decisional** no puede discutirse aisladamente. Es un concepto complejo que debe ser tratado en el marco de las relaciones interpersonales. También involucra las creencias de las personas y la confianza que tengan en los sistemas sociales en los cuales se insertan. Toda persona pertenece simultáneamente a muchos de ellos, de modo que la noción de identidad personal debe considerar este factor relacional. Tanto morir como sufrir una enfermedad mental incapacitante no es solo asunto individual; involucra a otros pues incluso quienes viven en aislamiento o soledad son parte de las comunidades.

La implementación de registros electrónicos apoyados por una adecuada logística algorítmica permitiría perfeccionar la planificación anticipada de cuidados e introducir rápida y confiablemente modificaciones según las circunstancias. El universo valórico de los grupos humanos puede sufrir modificaciones dependiendo de la autopercepción y de cambios en el cuidado de la salud. Un posible uso de la lógica algorítmica es brindar una **anticipación de escenarios** considerando una cantidad de variables muy superior a la que se tiene en cuenta al momento de expresar deseos, preferencias o necesidades. De esa forma, la planificación anticipada de cuidados puede enriquecerse con un factor de “*imaginación proléptica*” que permita elegir más de un curso de acción según las circunstancias. Es difícil que las personas puedan formarse ideas claras sobre los escenarios que enfrentarían, los apoyos sociales que necesitarían y los recursos a los que tendrían acceso. Sin embargo, la “**inteligencia artificial**” **predictiva**, disponiendo de informaciones sobre diversos aspectos o dimensiones puede predecir o prefigurar contingencias de modo vívido y comprensible. La formulación de una planificación anticipada de cuidados así ampliada sería más flexible y probablemente más efectiva.

“HOW TO LEAD OUR LIVES?” ADVANCE DIRECTIVES (ADS) IN AN ARISTOTELIAN APPROACH: AN ESSAY

José Dimas D'Avila Maciel Monteiro¹, Elcio Luiz Bonamigo², Rui Nunes³

Abstract: The question “how to lead our lives?” is a question about which life to live and is at the center of Aristotle’s ethical investigations in *Nicomachean Ethics*. Such a question seems not to get old, particularly when we express, in advance, decisions about future medical care to consent to or refuse, in advance directives (ADs), when we are unable to decide. The purpose of this investigation is to philosophically approach ADs from the question “how to lead our lives?”, admitting three possible approaches to aspects of Aristotle’s ethical investigation: 1st) emotions and ADs; 2nd) deliberation, deliberate choice, *phronesis* and ADs; 3rd) “How to lead our lives?” and ADs. It is concluded that a) the purpose of human life, according to Aristotle, is not simply to live, but to live humanly; b) the answer to the question “how to lead our lives?”, considering the categories of happiness (*eudaimonia*), emotions, virtues, practical wisdom (*phronesis*), deliberation, deliberate choice, and action, also involves the answer to the question about death and dying; c) Aristotle’s ethical investigation may be an alternative, although limited, to address ADs without the necessary appeal to moral rules.

Keywords: Bioethics, advance directives, personal autonomy, deliberation

“¿Cómo dirigir nuestras vidas?” Directrices anticipadas (DA) desde un enfoque aristotélico: un ensayo

Resumen: La pregunta “¿cómo llevar nuestras vidas?” es una cuestión sobre qué vida vivir y está en el centro de las investigaciones éticas de Aristóteles en la *Ética a Nicómaco*. Tal pregunta no parece envejecer específicamente cuando expresamos, de antemano, decisiones sobre la atención médica futura para consentir o rechazar, en directivas anticipadas (DA), cuando no somos capaces de decidir. El propósito de esta investigación es abordar filosóficamente la DA desde la pregunta “¿cómo vivir nuestra vida?”, admitiendo tres posibles aproximaciones a aspectos de la investigación ética de Aristóteles: 1) las emociones y la DA; 2) deliberación, elección deliberada, *phronesis* y la DA; 3) “¿Cómo llevar nuestra vida?” y el DA. Se concluye que a) el propósito de la vida humana, admitido por Aristóteles, no es simplemente vivir, sino vivir humanamente; b) la respuesta a la pregunta “¿cómo vivir nuestra vida?”, considerando las categorías felicidad (*eudaimonia*), emociones, virtudes, sabiduría práctica (*phronesis*), deliberación, elección deliberada y acción, implica también la respuesta a la pregunta sobre la muerte y el morir; c) La investigación ética de Aristóteles puede ser una alternativa, aunque limitada, para abordar la DA sin la necesaria apelación a reglas morales.

Palabras clave: bioética, directivas anticipadas, autonomía personal, deliberación

“Como conduzir nossas vidas?” Diretivas antecipadas (DA) numa abordagem aristotélica: um ensaio

Resumo: A pergunta “como conduzir nossas vidas?” é uma pergunta sobre qual vida viver e está no centro das investigações éticas de Aristóteles na *Ética a Nicômaco*. Tal pergunta parece não envelhecer, especificamente quando manifestamos, antecipadamente, decisões sobre cuidados médicos futuros a consentir ou a recusar, nas diretivas antecipadas de vontade (DAV), quando não formos capazes de decidir. A proposta desta investigação é abordar, filosoficamente, as DAV a partir da pergunta “como conduzir nossas vidas?”, admitindo três possíveis aproximações a aspectos da investigação ética de Aristóteles: 1^a) emoções e as DAV; 2^a) deliberação, escolha deliberada, *phronesis* e as DAV; 3^a) “Como conduzir nossas vidas?” e as DAV. Conclui-se que a) a finalidade da vida humana, admitida por Aristóteles, não é simplesmente viver, mas viver à maneira humana; b) a resposta à pergunta “como conduzir nossas vidas?”, considerando as categorias felicidade (*eudaimonia*), emoções, virtudes, sabedoria prática (*phronesis*), deliberação, escolha deliberada e ação, envolve também a resposta à pergunta sobre a morte e o morrer; c) A investigação ética de Aristóteles pode ser uma alternativa, ainda que limitada, para abordar as DAV sem o apelo necessário a regras morais.

Palavras chave: bioética, diretivas antecipadas, autonomia pessoal, deliberação

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Introduction

Planning our lives and achieving what we want, even if we are not sure we will achieve it, is a widely accepted idea. It is possible to argue that planning our lives stems from the universal capacity for reflection in choosing which life we should live(1,2). This idea is not new and may lead us to the Aristotelian idea of happiness (“the best life for a man to live”(3), the central object of the *Nicomachean Ethics*(4). However, this is about human happiness, human flourishing, not that of the gods. This is significant, as flourishing (or prospering) limits the scope of our capacities and our world: we are rational and mortal, immersed in contingencies, slaves of the sensations and emotions necessary for our survival. These are the conditions under which we can flourish and achieve any happiness, as well as fail(5).

We are not like the gods, noted Aristotle. They are always happy and blissful, they do not need to enter into contracts, return things received, take risks, or moderate their actions(4:X 8 1178b7-16). This is because they are not subject to contingencies, or circumstances; they don’t inhabit the world of indeterminacy(4:X 8 1178b7-16). Planning our lives and deciding which life to live is an eminently human task and we do it because the future is uncertain(4:VI 2 1039a7-8). This task is given to us by our nature, since all human activities, such as choices and actions, aim at a purpose and that is the good(4:I 2 1094a1-2).

“How to lead our lives?” is the question about which life to live, about happiness, and what is in question is not the knowledge of it, but what concerns the actions that lead to it and how we should practice them. Aristotle links happiness to virtue, as happiness seems to be a virtuous life(4:I 13 1102a5). The virtuous life involves practical wisdom (*phronesis*), emotions, deliberation, deliberate choice, and action.

“How to lead our lives?” is a question that does not get old, as we are continually faced with it, even when we are tempted to control the future, specifically when we express decisions about future medical care to consent or refuse, in advance directives (ADs), when we are unable to manifest them. ADs are an important tool for medical care

because, at the very least, they are an emblem of people’s autonomy and self-determination in relation to their own lives – manifest in their values, desires, and preferences – preventing them from undergoing futile clinical treatments.

Thus, the purpose of this investigation is to philosophically approach ADs from the question “how to lead our lives?”, considering three possible approaches to aspects of Aristotle’s ethical investigation: 1st) emotions and ADs; 2nd) deliberation, deliberate choice, *phronesis* and ADs; 3rd) “How to lead our lives?” and ADs.

Rehabilitation of Aristotle’s ethics in contemporary moral thought

The influence of Aristotle’s ethics on contemporary moral thought is recognized, and the reasons are diverse(2,5-7:330-1,8). Among them, the need to overcome the notion of “moral duty” and the recovery of the Aristotelian notion of “virtue”(6); the importance of Aristotle’s approaches to practical reason (along with those of Plato and the Stoics) and deliberation about how to use reason as a guide in human life, rivalling Kantian and utilitarian models(9:12).

The caveat, however, is that Aristotle has little or nothing to say about issues arising from many of our ethical concerns, and this must also be taken into account(5). Three of them are illustrative: 1st) regarding “living well”, the human Good, there is no rational basis that justifies the analytical identification between human happiness (happiness, prosperity, human well-being) and living according to virtue(5); 2nd) Aristotle does not offer us systems of rules for human actions, that is, he does not provide us with basic normative ethics. This is opposed to what modern thought would expect about the main result of the task of a philosophical ethics, to systematize the principles of human conduct(5,10:150); 3rd) the irreducible link between ethics and the structure of the Greek *Polis* can be an obstacle for Aristotelian ethics to gain a place in our world, since details of the explanation of the virtues presuppose the context of a structure that no longer exists(10:163).

In this sense, some internal difficulties and the limited scope of Aristotle’s ethical investigation, in

relation to contemporary moral conflicts, pointed out by scholars of Aristotle's ethical thought, undo any minimal claim to find in the answer to the question "how to lead our lives?" some trace of a guide to rules of action for ADs. If there are frustrations for anyone approaching Aristotle's ethical investigation, one of them is not finding, in a forceful way, rules of action(11,12). In this sense, following, as a reader, some aspects of his ethics is enough to give credence to MacDowell's consideration of the advantage of studying an important philosopher of another era because it is possible to perceive that we do not need to swim with the tides of our own time(11).

Purpose of human life: the human good, happiness and a peculiar way of living...

If we can plan our lives considering them as a complete life, as a process, is there a purpose for human life? A purpose? If so, what is it? Is it one's own way of living? Is there a better life to be lived? Are there reasons to seek it out? If there is a better life to be lived, then it seems reasonable to pursue it and unreasonable not to pursue it. After all, is there anything better to be desired than to live well?(13). But what does this good consist of?

The clue to investigate such questions is given by Aristotle at the beginning of the *Nicomachean Ethics*(4), starting from a common opinion about human things, that all activity and all investigation, as well as all choice and action, aim at a good, an end. As are many arts and sciences activities, so are their purposes. Medicine is health, just as strategy is victory. However, about our actions, there is a good before all others, a good desired by itself and all other goods are sought in terms of it. If the knowledge of this good brings great influence on human life, then Aristotle undertakes an investigation with the aim of determining what this good is, as well as which science or activity it is the object of. This must be political science, for it embraces all others and its purpose also includes that of others(4:I 1-2). The human good is the end of political science. But still, what does this good consist of?

Aristotle's investigation is faced with another common opinion, that the beautiful and just actions seem varied and vague, and can be consid-

ered in a conventional and unnatural way. The same also happens with goods, since it is observed that some people have already perished because of wealth. Starting from this premise - fine and fair actions seem to be constituted in a conventional way and not in a natural way - Aristotle claims that such an investigation will reach truths in general, approximate lines, as well as goods, since the nature of the subject does not allow more than that(4:I 3 1904b11-27), which is a distinctive aspect of his ethics.

The good, the end to which all actions aim, is identified with happiness. Both common people and sages believe that living well and taking action equal happiness. However, opinions differ about what happiness really is. Some link it to pleasure, wealth, or health; others to honours, and still others to the contemplative life. But these goods seem not to be chosen for their own sake, but chosen for the sake of happiness(4:I 7 1095a218-26). There must be, for Aristotle, something peculiar to the human being, something that distinguishes him. And he concludes that happiness is established as an activity of the soul in conformity with virtue. It involves a certain way of life that spans a lifetime, just as one swallow does not make a summer, just as one day does not make a human being happy(4:I 7 1098a7-19).

It is not just any way of life as noted by Lawrence, but a way peculiar to human beings, acting rationally (thinking and emotions), implying a rational choice and the virtues of that choice. It is what distinguishes us from other living beings. One of the sophistications of the human function, living well or acting well, is that it refers to real living(13). According to Kraut, even if a theory about how to conduct our lives must be submitted to intellectual tests, it must do even more: it must be able to be lived and, in a way, the human good defined by Aristotle points in this direction(14).

A door is opened here to approach, in general terms, an aspect involving ADs. If Aristotle is correct in considering happiness to be living well in a complete life, not episodic, then living in a certain way may also imply dying in a certain way. Perhaps it is less about consenting or refusing treatments in future medical care and more

about which life we want to live. It is less about treatment and more about which life to live.

Virtues, emotions, deliberation, deliberate choice, actions, practical wisdom (*phronesis*) and the prudent person (*phronimos*): what is within reach of our choices and actions?

If living well and being happy involve virtuous actions, then what constitutes happiness? Aristotle's task, after defining happiness as an activity of the soul in accordance with virtue, is to investigate it (4:I 13 1102a6-7). Rather, he approaches the human soul in general terms and divides it into two parts: a rational one; another non-rational. Of this, there are two parts: the vegetative, and the appetitive and desiring, participating in a certain way in reason. The vegetative part is concerned with nutrition and food; the appetitive and desiring partakes, to a certain extent, of reason, for it is capable of obeying reason, as well as capable of not obeying it. If there are people who act well, obeying reason and the rational part of reason, in the same way, they can act against reason. As for virtue, it is also divided into two kinds: intellectual and moral virtues. The first is mostly given by teaching, such as wisdom (*sophia*) and practical wisdom (*phronesis*); the second is given by habit, like generosity, temperance, courage, and justice. These virtues we acquire by their exercise, for we learn to act virtuously by acting virtuously. In the same way, we learn to be courageous by acting courageously. However, the same things that make us courageous can make us vicious, acting cowardly, as we get used to facing dangerous situations or fearing them (4:I 13 1102a25-II I 1103b26).

Aristotle's investigation of virtue proceeds from the premise that it does not aim at theoretical knowledge but at how we become good. Therefore, it is necessary to investigate what they refer to and how we should practice them (4:II 2 1103b27-1104a26). It also starts from an accepted principle: "acting according to right rule" (4:II 2 1103b32). However, it must also be admitted, such an investigation is limited in scope, for what involves particular actions and useful things is not exact. The agent does not have a precept or rule on which he must act as a basis; he will consider the circumstances.

Moral virtues can be destroyed by excess and defect, just as vigour and health can. Too much exercise or too little food destroys vigour and health, and so does too little exercise and too little food. As for courage, he who fears all things becomes a coward; he who fears nothing becomes reckless. Courage, a virtue, is destroyed by excess and defect and preserved by the mean. One who accustoms himself to enduring fears and facing them is courageous, and by acting in this way, he becomes more capable of bearing and facing fears. The brave man rejoices, or at least does not suffer, with the fear he faces; the coward suffers from fears. Thus, the moral virtues relate to pleasure and suffering. Because of this, we do evil deeds; because of that, we stop doing beautiful deeds. And if the moral virtues relate to actions and emotions and if these are accompanied by pleasure and suffering, then it confirms that moral virtues concern pleasure and suffering (4:II 2 1104a11-3 1104b28).

In the direction of understanding what virtue is, Aristotle will investigate whether it is even a certain type of disposition. Regarding the generated states of the soul, virtue must be one of them: emotions, capacities and dispositions. By emotions, Aristotle considers anger, fear, envy, hatred, pity, ambition, among others, and, in general, everything that results from pleasure and suffering; by capacity, the way we are affected by emotions, the capacity to feel pity, to feel hate; by disposition, the way we behave in the face of emotions. Regarding anger, if we feel it excessively, we act badly; if we feel it moderately, we act well. So, the virtues are not emotions, as we are not virtuous or vicious because of emotions. Also, virtues are not capacities, first, because they are independent of deliberate choices, and virtues involve certain choices; second, because we don't say that we are good or bad by the capacity of feeling emotions. It remains for virtue to be a certain type of disposition, and this will be the one by which the human being becomes good, acts well, performing what is proper to him, the human good (4:II 5-6 1107a3).

But what is the nature of moral virtue? What justifies it as a means (middle ground, middle term)? Aristotle considers that over everything that "is continuous and divisible it is possible to take

more, less, or an equal amount, and that either in terms of the thing itself or relatively to us; and the equal is an intermediate between excess and defect" (4:II 6 1106a26-28). By the intermediate, in relation to the object itself, he understands it to be the same in all cases, according to arithmetic proportion. Between 10 and 2, which represent a lot and a little, 6 is the middle term. By the intermediate relative to us, he understands it not to be fixed in all cases. The coach will not prescribe heavy exercise for a beginner athlete, just as he will not indicate light exercise for an experienced athlete. What is excess for one will seem light to another (4:II 6 1106a29-b4). In this sense, one can feel fear, confidence, and anger too much or too little, and both are not the right way to feel, but it is the right way, the middle ground, "to feel them at the time, with reference to the right objects, towards the right people, with the right motive, and in the right way" (4:II 6 1106b20-22). For Aristotle, the virtues are related to emotions and actions, aiming for the middle ground. Missing the target is easy, hitting it is difficult. From this path, virtue is defined by Aristotle as:

is a state of character concerned with choice, lying in a mean, i.e., the mean relative to us, this being determined by a rational principle, and by that principle by which the man of practical wisdom would determine it. Now it is a mean between two vices, that which depends on excess and that which depends on defect (4:II 6 1106b36-a1-4).

If moral virtue is a deliberate choice, what constitutes a deliberate choice? Aristotle's investigation of deliberate choice begins by considering what does not constitute it (4:III 2). It is not common to irrational animals; it is not appetite, since the latter is opposed to the former; it is not wanting, because we don't deliberately choose impossible things. Likewise, they are not opinions. In this sense, it seems that deliberate choices concern the deliberative desire of what is in our power and that they are directed towards an end and the means to that end (12). Aristotle establishes deliberate choice as involving thought and reflection, and seems to refer to that which is chosen in preference to other things (4:2 1112a17).

Deliberate choice is preceded by deliberation. This is a kind of investigation, and Aristotle asks himself about what is possible to deliberate (4:III 3). Not much remains for deliberation. Among those listed by Aristotle, the following stand out: one does not deliberate on eternal objects, the universe, for example; nor in relation to what happens sometimes one way, sometimes another, rains and droughts, for example; One does not deliberate about all human things, as the way for a people to govern itself. The ones that remain are those that are in our power, within our reach to do. Deliberation "is concerned with things that happen in a certain way for the most part, but in which the event is obscure, and with things in which it is indeterminate" (4:III 3 1112b8-10). Deliberation is not about ends, but about means. The purpose of medicine is health, and a doctor does not decide whether or not to achieve this end; he decides what means to use to achieve this end more easily and in the best way. The principle of action is in us, but the object of deliberation is not the end to be attained, but the means conducive to it (4:III 3 1112b12-1113a8). Price considers deliberation to be an intentional activity directed towards an intentional action (15).

The object of deliberation is the same as that of deliberate choice, but that of deliberate choice is determined by deliberation (4:III 3 1113a3-4). However, Bobzien points out that, although the things in our power are common among them, the object of deliberate choice is not the same as that of deliberation, since the object of deliberation is what the agent deliberates about; that of deliberate choice is what the agent came to choose. The first is undefined; the second is determined. Deliberation offers the courses of action resulting from the investigation. Deliberate choice decides on the course of action established by the deliberation or not, and this will imply voluntary action. Voluntary actions are the object of praise or censure; the involuntary ones of forgiveness and sometimes pity. These happen because they are forced or out of ignorance and their principle is external to the agent; and no responsibility can be attributed (12). Voluntary actions are those whose principle of action is in the agent, it is in his power to act or not (4:III 1110a15-18). Thus, human agency involves deliberate choice and, through it,

the connection between voluntary actions, virtues, and vices is drawn(12).

If it is right for us to choose the middle ground (mean), avoiding excess and lack, and if this concerns the right rule (right reasoning), then what is the nature of this? This is Aristotle’s investigation in Book VI of the *Nicomachean Ethics*(4): what is the right rule (right reasoning) and the standard that determines it(4:VI 1 1138b34). He begins his examination by considering some observations about the soul and its two parts: a rational one and another non-rational(4:I 13). Regarding the part of the soul endowed with reason, he separates it into two parts: one that enables us to contemplate immutable things and the other that enables us to contemplate variable things, which are subject to changes. The first can be called scientific and the second calculative, since calculating and deliberating are the same, and one does not deliberate about immutable things(4:VI I 1139a5-14). According to Bobzien, this explains why the second part is responsible for deliberation, and through it, determines the means by which the ends will be achieved. Practical wisdom (*phronesis*) is the virtue of the deliberative part(12).

Practical wisdom (*phronesis*) is one of the intellectual virtues. In general terms, Aristotle considers it good deliberation, and the person endowed with practical wisdom (the *phronimos*) is the one who deliberates well. However, practical wisdom cannot be scientific knowledge and cannot be art (*techne*). First, because variations in knowledge are not allowed; second, because in art, what is in question is making and not acting. What remains, then, is that practical wisdom, with regard to actions taken for the sake of human good, is a rational quality that leads to truth, but not to immutable truths(4:VI 5), since there is another kind of wisdom, according to Aristotle. This is philosophical wisdom (*sophia*). It combines intelligence and scientific knowledge, the knowledge of the most sublime things. Practical wisdom relates to human actions and things amenable to deliberation(4:VI 7).

If practical wisdom (*phronesis*) relates to human things, then it relates to moral virtue. Aristotle considers that moral virtue is the disposition in which right rule (right reasoning) is, and practical

wisdom (*phronesis*) is right rule (right reasoning) concerning action. Thus, moral virtue is a disposition in accordance with practical wisdom (*phronesis*)(4:VI 13 1144b24-27). According to Aristotle, although practical wisdom (*phronesis*) had no practical value, “we should have needed it because it is the virtue of the part of us in question; plain too that the choice will not be right without practical wisdom any more than without virtue; for the one determines the end and the other makes us do the things that lead to the end”(4:VI 13 1145a3-5).

Another door opens to approach ADs through Aristotle’s ethical investigation. From the ingenious articulation between happiness (living well), virtues, emotions, practical wisdom, deliberation, deliberate choice, action and the moral agent, it is possible to analyse the role of emotions in ADs and their relationship in the manifestation of desires, values, and preferences of people, as well as what is in our power to deliberate about ADs.

ADs in an Aristotelian approach

The common frustration in modern philosophy with regard to Aristotle’s ethical inquiry not providing external justification of ethics, that is, its objective correctness, is clear(11). The question about such accuracy was not asked by Aristotle. Aristotle’s ethical investigation does not provide us with recourse to universal rules of action, in a robust theory of action, because, at least, a rule of action is not extracted from the controversial doctrine of the middle term (mean), even if virtue as a middle ground between two vices guides virtuous action(13). Furthermore, the origin of the action is in the agent, and it is up to him, in a way, to be the “rule” of the action. If this is correct, what can Aristotle’s ethical investigation offer to the approaches about ADs if their foundations rest on theories based on moral principles such as the principle of respect for people’s autonomy?

We intend here, in general terms, to consider the ADs, based on some of Aristotle’s claims in the *Nicomachean Ethics*(4) about feeling and acting, admitting three possible approximations: 1st) emotions and the ADs; 2nd) deliberate deliberation and choice, and ADs; 3rd) “How to lead our lives?” and the ADs.

Emotions and ADs

ADs represent the human capacity to choose and act autonomously (as self-government). Such autonomy implies, in a sense, not succumbing to inclinations, emotions, so that anticipated choices about future medical care rationally express the desires, values and preferences of the people who elaborate them. In addition, anticipated choices can reveal a certain justified security about an uncertain future without all the risks that result from facing sensitive situations about death and dying. So, what does it mean to integrate emotions closer to the ADs process?

Emotions occupy an important place in Aristotle's ethical investigation. As noted by Zingano, in the practical domain, emotions play a significant role in moral action, even though they contrast with reason. In moral action, it follows that emotional and non-cognitive elements are present. Emotions, he goes on, must be previously educated by moral habit, so that reason can give them the correct direction(16:23-4). In the same sense, Molewijk et al., consider that in Aristotle, emotions move human thought and actions, and practical wisdom is not constituted by the abandonment of emotions, but by the development of emotions adequate to the concrete situation, where the choices and actions operate(17).

With regard to emotions, what considerations are possible about ADs? One of them is the instability of the decisions expressed in ADs, one of the most common criticisms. If people's desires, values and preferences can change over time, what guarantees the ADs moral authority to be required in the future? Stability in ADs decisions is one of the criteria for their support, and the manifest expression of self-determination by people assumes that they are free and reasonable. However, what is the role of emotions in the ADs process? Would they indicate the inevitable instability of decisions? Yes, if we admit, at the origin of ADs, that the idea of rationally controlling decisions about future medical care is correct. No, 1st) if we consider the expectation of control over such care as unrealistic (perhaps it would be more effective to admit that human decisions are permeated by feeling, acting and indeterminate contexts); no, 2nd) if we admit with Bobzien that emotions are as

human as reason(12). People's desires, values, and preferences do not seem to arise exclusively from rational inquiry.

Bringing ADs closer to an Aristotelian approach here may imply their shift to the practical domain of Aristotle's ethical investigation, recognizing that emotions are part of human choices and actions. This is an unavoidable risk. The process that constitutes the elaboration of ADs involves emotions that do not weaken them but make them authentic. ADs are fixed in relation to the stability of decisions, but are always required in the indeterminacy of circumstances. When choosing in advance about future medical care, people deposit in them not only the ways of understanding life and a happy life, but also the ways of feeling and acting. Decisions in ADs do not seem to occur despite emotions, but with them.

Deliberation, deliberate choice, phronesis and ADs

What constitutes the ADs elaboration process? What kind of decisions are involved? What is in people's power to decide? The ADs express, among other things, the idea of controlling our lives, determining, when possible, which life to live and which death to die, including. Decision-making strategies in medical care are common(18). For end-of-life care, which involves ADs, such strategies serve as a guide so that decisions involving the patient, family, and health care professionals express the patient's desires, values, and preferences and cause the least possible suffering to the family and to the professionals. As previously highlighted, the intended approach here is not intended to consider such strategies, but to address the process of elaborating ADs from what is within our power to deliberate, as formulated by Aristotle.

Deliberation is an inquiry that precedes deliberate choice. In Aristotle, only things within our power, and which may be different from what they are, are subject to deliberation. Death is an end set by nature, and if it is not within our power to decide whether to die or not, then what would be left for ADs if we restrict them to end-of-life care? Perhaps just deliberating about the means by which we wish to deal with death and dying, here and now, and projected into the uncertain future. It is

an attractive idea, but it seems ineffective, because for the moral agent, the field of manoeuvre for deliberation in ADs is restricted, since it remains for us to deliberate on the means and not on the ends, in the same way that the doctor does not deliberate whether he will cure or not, but only about the means by which he will reach the established end: the health of the patient.

Thus, in relation to the process of elaborating the ADs, it seems clear that it is up to the person in this process to deliberate and choose the course of action for the future since they know the current circumstances where their manifestations about consent or refusal of future medical care rest. However, it is worth mentioning that the agent deliberates and chooses something that will happen in the future, they do not have control over the action, as it is about the control over the choice. We can consider, on the other hand, that if deliberate choices operate in contingencies, in particular circumstances, it is impossible to assume what the person would want in the situation of no longer choosing which medical care to consent to and which to refuse; they would need to be in a future situation. In this way, we deliberate and choose in ADs in view of the circumstances in which we are.

In the practical domain established, we deliberate, choose, and act, here and now, and nothing else. In this domain of uncertainties, the practical wisdom (*phronesis*) of the virtuous person (the *phronimos*) will indicate, weighing reasons, which emotions and actions are correct, taking into account what is appropriate in each situation, in what way, in relation to whom and with what end(4:II 2 1104a32;3 1104b21-24;6 1106b20-23). In a sense, it is the yardstick for good deliberation, deliberate choice, and good action(15). Roughly speaking, it is up to the person in the process of preparing an ADs to establish, in the manner of a virtuous person, 1st) whether or not to prepare the AD; 2nd) through deliberation, weighing reasons, what is the most appropriate course of action for the circumstance, in view of the desired end; 3rd) deliberate choice, deciding whether the course of action offered by the deliberation will be chosen; 4th) that the choice made will be fulfilled in the future, but still dependent on a concrete circumstance. Despite the AD be-

ing constituted in view of the uncertain future, it will always be required in the present.

Good deliberation, deliberate choice, and good action, according to Aristotle, will always depend on the pairing of moral virtues with practical wisdom (*phronesis*), as noted by Russell(19). Roughly speaking, good deliberation, deliberate choice and good action in ADs require education for virtues (morals and *phronesis*), not to learn deliberative strategies, but of learning how to live well and die well, becoming in people sensitive to circumstances and facts(19). As rational agents, Lawrence highlighted, we aim to obtain the best, and this seems to be good living. The task of reason is both to seek what correctly constitutes good living and to maintain it. Good living is expressed by the constancy of virtuous actions(13).

"How to lead our lives?" and the ADs

"How to lead our lives?" seems to encompass, in a broad sense, the human capacity to elaborate projects on which to live and carry them out through choices and actions. Although it leads us to elegant ideals for these projects, such as the perfect life or what life should be, the question that never gets old seems to be limited to the contexts of the human world. This seems to be that of the possible, the contingent, subject to the indeterminacies of the human being. Not without purpose, Aristotle considered that ethical investigation does not aim at knowledge, such as knowing what virtue is, but aims to make us good(4:II 2 1103b26-28).

The central place assigned to reason in the contemporary world, as pointed out by Thiel, prompts people to take responsibility for their lives and deaths, extending this place to the point where subjective approaches to death and dying are no longer possible(20). ADs, to a certain extent, express part of this perspective, as they create the feeling that even death can be dominated, neglecting the existence of a body, with its desires, values, and preferences. The search for mastery of the future, although far from being achieved, is a human need.

The manifestation of wills, desires, values, and preferences, through ADs, comes close to the

determination of conduct for an uncertain risk situation, in which the patient, family members, and the health team contribute to the predictions. However, the virtual reality that is planned may not be the reality that will actually be presented. Possible safety mechanisms include the adoption of precautionary measures, such as that consist of designating a well-informed legal representative (substitute decision-maker), as well as care by health care professionals who are prepared to interpret unforeseen situations, so that they can be adapted as closely as possible to the person's wishes. With this, the total control of the person's autonomy through the ADs, although it can contribute decisively to their benefit, does not fail to present clear limitations. Perhaps this is one of the challenges to the principle of individual autonomy: not neglecting concrete contexts, real people, and existing relationships.

Aristotle's ethical investigation in *Nicomachean Ethics*(4) expresses the recognition that the practical domain is a field of imprecision and, therefore, the truth is by approximation. Perhaps the possible approach to the question "how to lead our lives?" in the context of ADs is to recognize that a happy life is a long process of virtuous choices and actions, here and now, and that even in the face of their consistency, we are always subject to failure. Therefore, Aristotle insists on education for virtues from an early age. However, nothing is guaranteed. Perhaps this is one of the few possible contributions of the Aristotelian approach to ADs, considering the question "how to lead our lives?", Wiggins points out that under no circumstances can the moral agent resort to a rule to determine what to do(21). Like the archer who aims his arrow at the target, maybe we also aim at which life to live. Just as the archer is not sure if he will hit the target before shooting the arrow in its direction, we will not know how to lead our lives without the choices and actions that lead to it. The aim is a happy life and good living.

Final considerations

In a way, this is the framework in which we intend to draw lines of approximation between the Aristotelian question "how to conduct our lives?" and ADs. In this investigation, we were interested in what is involved in the question "how to lead

our lives?" in a complete life, in each choice, here and now, with human limitations, with the indeterminacy of circumstances, with the uncertainty of the future, with death and dying.

Therefore, perhaps the ambitions to control future scenarios that address ADs derive from the desire to control the practical domain in which our choices and actions operate. Perhaps, also, ADs can contribute to making the life we live complete, through the most appropriate way of consenting to or refusing future medical care, with our desires, values and preferences, in short, with our biographies, in the appropriate context, in relation to the appropriate things, in the appropriate way, in relation to the appropriate people, with the appropriate emotions, at the appropriate time. Perhaps the ADs involve decisions with deliberate choice preceded by desire, deliberation, weighing reasons, to find the most appropriate course of action and achieve the desired end, such as dying without suffering. Aristotle, agreeing with Plato, emphasizes the importance of being educated from an early age to rejoice and suffer with to appropriate things, as noted by Hursthouse(22,4:II 3 1104b13).

Thus, we conclude that the purpose of human life, according to Aristotle, is not simply to live, but to live humanly; that the answer to the question "how to lead our lives?" also involves considering death and dying; and that Aristotle's ethical investigation may be an alternative, although limited, to address ADs without the necessary appeal to moral rules.

These were the approaches considered and pursued, from an uncontroversial position of Aristotle's ethical investigation in *Nicomachean Ethics*(4): we do not deliberate well, choose deliberately and act well despite emotions, but with them.

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MARGINALIZING QUALITATIVE KNOWLEDGE: ETHICAL AND EPISTEMIC TENSIONS IN MEDICAL RESEARCH CULTURES

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Abstract: This paper examines the challenges of qualitative research in medical contexts through our position as qualitative researchers, bioethicists, and ethics committee members in Turkey. We explore how biomedical paradigm dominance shapes qualitative research evaluation in medical settings, arguing that qualitative understanding is essential to medical knowledge production, not merely a methodological choice. Through experiential insights, we identify critical issues: insufficient methodological awareness among researchers, limited recognition of qualitative paradigms by ethics committees, and persistent epistemic injustice in evaluation processes, even within traditionally receptive fields. These challenges arise from deeper philosophical tensions rather than procedural difficulties. We propose reflexivity as both a methodological requirement and an ethical virtue to address qualitative research marginalization in medicine. Our analysis contributes to discussions about the relationship between ethics and science in qualitative research while offering practical insights for improving evaluation and support of qualitative methodologies in medical contexts.

Keywords: qualitative research, bioethics, research ethics, epistemic injustice, reflexivity

Marginando el conocimiento cualitativo: tensiones éticas y epistémicas en las culturas de investigación médica

Resumen: Este artículo examina los desafíos de la investigación cualitativa en contextos médicos, desde la perspectiva de investigadores cualitativos, bioeticistas y miembros de comités de ética en Turquía. Exploramos cómo el predominio del paradigma biomédico influye en la evaluación de la investigación cualitativa en entornos médicos, argumentando que la comprensión cualitativa es esencial para la producción de conocimiento médico, no una mera elección metodológica. A través de perspectivas experienciales, identificamos problemas críticos: la insuficiente conciencia metodológica entre los investigadores, el limitado reconocimiento de los paradigmas cualitativos por parte de los comités de ética y la persistente injusticia epistémica en los procesos de evaluación, incluso en campos tradicionalmente receptivos. Estos desafíos surgen de tensiones filosóficas más profundas que de dificultades procedimentales. Proponemos la reflexividad como un requisito metodológico y una virtud ética para abordar la marginación de la investigación cualitativa en medicina. Nuestro análisis contribuye al debate sobre la relación entre la ética y la ciencia en la investigación cualitativa, a la vez que ofrece perspectivas prácticas para mejorar la evaluación y el apoyo a las metodologías cualitativas en contextos médicos.

Palabras clave: investigación cualitativa, bioética, ética de la investigación, injusticia epistémica, reflexividad

Marginalizando conhecimento qualitativo: tensões éticas e epistêmicas nas culturas de pesquisa médica

Resumo: Esse artigo examina os desafios da pesquisa qualitativa em contextos médicos, através de nossa posição como pesquisadores qualitativos, bioeticistas e membros de comitês de ética na Turquia. Nós exploramos como a dominância do paradigma biomédico molda a avaliação de pesquisa qualitativa em contextos médicos, argumentando que a compreensão qualitativa é essencial para a produção do conhecimento médico, não meramente uma escolha metodológica. Por meio de experiências pessoais, nós identificamos questões críticas: consciência metodológica insuficiente entre pesquisadores, reconhecimento limitado de paradigmas qualitativos por comitês de ética e injustiça epistêmica persistente em processos de avaliação, mesmo em campos tradicionalmente receptivos. Esses desafios surgem de tensões filosóficas profundas mais do que de dificuldades processuais. Nós propomos reflexividade tanto como um requisito metodológico como uma virtude ética para abordar a marginalização da pesquisa qualitativa em medicina. Nossa análise contribui para discussões sobre a relação entre ética e ciência em pesquisa qualitativa ao mesmo tempo em que oferece insights práticos para melhorar a avaliação e o apoio a metodologias qualitativas em contextos médicos.

Palavras chave: pesquisa qualitativa, bioética, ética em pesquisa, injustiça epistêmica, reflexividade

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Introduction

The integration of qualitative research methodologies into medical research has evolved significantly over the past decades, moving from a peripheral status to a more central position in health care knowledge production(1). Many crucial aspects of healthcare - including patient experiences, decision-making processes, and delivery systems - require approaches that capture their complexity and contextual nature(2). Qualitative research offers unique capabilities in this regard, providing insights into the human dimensions of health and illness that complement and enhance traditional biomedical approaches(3,4). However, challenges persist in the integration of qualitative methodologies in predominantly biomedical research contexts. These challenges are particularly pronounced in settings where the biomedical paradigm maintains strong institutional dominance, shaping everything from research design to ethical review processes(5). This is particularly evident in Turkey, where our position as qualitative researchers, bioethicists, and ethics committee members highlights the systemic barriers to qualitative inquiry in medical contexts.

This study examines these challenges through our unique position in the Turkish medical research environment. Our experiences align with Dwyer and Buckle's concept of the "space between" inhabiting both insider and outsider positions simultaneously, offering insights into systemic challenges facing qualitative research within institutional structures designed for biomedical research(6). This positioning reveals power dynamics and institutional frameworks that shape research practices(7). In this context, we posit that the role of a bioethicist necessitates the facilitation of dialogue and the construction of a bridge between the qualitative researcher and the ethics committees(8). Our experiences and insights into the intricacies of this relationship, both from insider and outsider perspectives, are believed to contribute valuable insights to the field.

The primary focus of this article is qualitative research; however, it is imperative to recognize that in disciplines such as medicine, where human understanding is of paramount importance, the importance of qualitative understanding goes

beyond the realm of research methodology. This claim highlights the indispensability of qualitative orientation to contexts involving concepts such as meaning and understanding. Therefore, it is insufficient to view ethical problems in qualitative research only as a matter of technical processes. When discussing the ethical dimensions of qualitative research in medicine, it is essential to consider an ethical awareness that extends beyond conventional ethical procedures, from the initiation of a research project to its publication. The contribution of qualitative understanding to medicine possesses ontological and epistemological significance, underscoring the ethical implications inherent in the subordination of these research endeavors within medical domains. In the following section, we briefly address the ontological, epistemological, and ethical dimensions of qualitative understanding (and not merely qualitative research) in medicine. We believe that this section is also fundamentally important for experiential insights and discussions.

The Ontological, Epistemological, and Ethical Meaning of Qualitative Research in Medicine

Contemporary philosophers of medicine, such as Fredrik Svenaeus, as well as great physician philosophers of the past, such as Galen, emphasize in their reflections on medicine that medicine cannot be seen simply as a reductionist application of technical (or scientific) knowledge(9,10). In this context, medicine is not merely the reduction of existing knowledge to practice but a field of understanding and action that extends beyond this(11). The humanistic aspect of medicine, which should not be reductionist, has been emphasized since Hippocrates(12). However, while the technocratic reduction of medicine's approach to the individual in the modern period is a frequently criticized issue, it has been pointed out that professionalism in medicine should be rebuilt in a humanistic sense(13–16). The definition of health by organizations such as WHO or the person-centered medicine approach, which recently emphasizes the importance of understanding the first-person experiences of patients in different contexts (diagnostic, adherence, outcomes), is also seen to contain a strong emphasis on the aspect of medicine that should not be reductionist(17–19). These findings indicate that the effort to orient patients

and understand them in the field of medicine and medical research should not be reduced to a single paradigm. As educators and researchers working in fields such as medical humanities and biomedical ethics, we can say that, at least in our country, we are appreciated for emphasizing humanistic approaches, the importance of understanding the patient holistically, and the importance of ethical approaches and philosophical perspectives within the medical climate. However, when it comes to finding a place for these as a value in practice or research, we can express that we regret to see that these are generally considered as intellectual fields of endeavor that do not go much beyond appreciation(14,16,20). We have even been exposed to discourse from some basic science fields of medicine in which this endeavor is “paramedical work”. First, we do not take offense at being exposed to such discourses, but we can express our sadness at being exposed. In this discourse, we can say that we find it ironic that the effort to understand human beings in a multidimensional way with different dimensions, which we think is inherent in medicine, is interestingly reduced to a secondary or insignificant position, not inherent to medicine. Almost parallel to this, it is possible to express regret that qualitative research is also evaluated in a secondary position within the current medical paradigm. This problem stems from an insufficient understanding of the ontological and epistemological position of qualitative research in medicine. The challenges we face as researchers, bioethicists, and ethics committee members are closely related to this gap. Before sharing our experiences, we briefly note that qualitative research has strong ontological, epistemological, and ethical justifications for medicine. In addition, when considering our endeavor in the field of medical sciences, we would like to state that we do not see quantitative or qualitative methods as the opposite or alternative of each other. These studies are important complements of a whole and sometimes express enriching ways of looking at the same thing or reality(21,22).

“What is it like, from the patient’s perspective, to suffer from illness? Answering this question is crucial to make sense of medicine as an endeavour struggling with other problems and having other aims than merely those of an ap-

plied biology.”(11)

Medicine is not only a science but also a field of action to alleviate human suffering, starting from understanding and making sense of it. We can say that understanding and making sense of pain and acting based on this constitute the basis of the ontological orientation of medicine. This makes medicine an intensely relational field(23,24). When we think about the dimensions of understanding and signification and the relational dimension of medicine, we see that these dimensions cannot be easily reduced to a quantitative dimension. Therefore, when we look from this basis, we realize that qualitative orientation (or understanding) has a fundamental ontological meaning for medicine, especially for professionals working in this field, even before we come to the issue of “formal research”. This ontological basis inevitably pushes us toward a methodology that aims to understand and make sense of things that cannot be easily reduced to quantitative data in epistemological terms. While we position qualitative orientation as having primarily ontological and epistemological meaning, this is not a dualist view that excludes the biomedical perspective. The reason for our emphasis on the ontological and epistemological meaning of qualitative orientation is that despite positive developments in qualitative research (more evident in fields such as nursing), unfortunately, it is still common in mainstream medicine to position qualitative orientation as secondary or external(1). We believe that this problem is even more prevalent in developing countries, such as Turkey. We hope that some of these reasons will be more easily understood when reading the sections on our experiences. We now briefly examine qualitative research on the dimensions of meaning and signification. Medicine is inherently too complex to be reduced to a single methodology(16). As each patient is a unique and dynamic being, there is an inevitable gap between scientific knowledge of the general and universal and the application of this knowledge to specific situations. Understanding an individual requires grasping how universal principles interact with particular situations while attending to relevant contextual details(16). In fact, whether the physician realizes it or not, he/she carries these closely related tensions in his/her identity. A medi-

cal professional is inevitably a representative of a dual identity, equipped with scientific knowledge on the one hand, but also oriented as a practitioner toward other individuals of whom they/are a member. We think that clinicians are quite aware of this in their daily practice, but when it comes to scientific studies, for some reason, the acceptance of the absoluteness of the universal or scientific still predominates(25). However, the complexity of medicine and the people it deals with make methodological pluralism a necessity for research. In this context, it is important to be aware that a complex field of social reality such as medicine cannot be made sense of only with a positivist or post-positivist approach, and it is important to be aware of approaches such as constructivism or scientific realism. In this respect, it is necessary to take into account that medicine is a field where there are different layers of reality, as some authors have stated, and research to access them can be complex in this context(22). Through a variety of approaches, the experiences and knowledge of the individual who produces meaning and lives in a wide world of meaning becomes an extremely important subject of study. Therefore, it becomes an important issue to understand the meaning produced by the individual and the impact and meaning of this meaning in the field of social reality, rather than revealing a truth that just stands there. For instance, understanding a patient's experience—especially when it does not neatly align with the biomedical paradigm—requires a distinct effort to bridge this epistemic gap. However, this does not require strictly adhering to the biomedical model, nor does it mean abandoning it altogether. Rather, an epistemically humble attitude and an awareness of different perspectives will suffice.

When we examine the ethical implications of the marginalization of qualitative research, we see that this is not only a problem of methodological choice but also an attitude with important ethical consequences. The subordination of qualitative research and participants' experiences can be seen as a fundamental problem of injustice(26). This situation prevents the voices of disadvantaged groups from being heard and damages the principles of justice and beneficence, which are the basic ethical principles of medicine. The connection between

qualitative understanding and medical ethics, as Svenaeus emphasizes, is grounded in the fact that medicine is not a purely technical practice, but a field of understanding and action that extends beyond this(9). As Bleakley emphasizes in the field of medical humanities, the endeavor to understand the human being is a fundamental goal for both medical humanities and bioethics(27). This inevitably makes qualitative research an indispensable tool of understanding and signification for these fields.

Before sharing our experiences, we would like to emphasize that qualitative research in medicine is not only a methodological choice but also a requirement of the ontological structure of medicine, epistemological pluralism, and ethical responsibility. Considering the wide scope of medicine, the fact that it includes many different disciplines together, and that it interacts with different stakeholders as an institution, it is important to be aware that different views of reality and models of knowledge production may have different meanings in terms of ethics and values. It is a fundamental requirement for qualitative research to reach the position it deserves, especially for this awareness to become established in individual researchers, research ethics committees, journal editors, and academic institutions.

Experiential Insights from Inside and Outside

Being a bioethicist in the field of medicine offers us the experience of being in different positions. Participating in educational activities, including research and publication ethics, conducting scientific research, and serving on different ethics committees, depending on the nature of our field, are the main activities. In this context, we think it would be appropriate to present our experiences under headings related to our experiences in these fields of study. We would like to state that all these experiences have ontological, epistemological, and important ethical meanings. Key findings from our experiences include: weak methodological awareness among qualitative researchers; limited recognition of qualitative paradigms by ethics committees; positivist influences in evaluations; researchers' reluctance to defend their methodologies; and epistemic injustice in publication processes, even within traditionally receptive fields.

Problems before the ethics committee or the unbearable lightness of being a qualitative researcher!

As qualitatively oriented bioethicists, we've observed that qualitative research faces serious theoretical and practical problems. Despite its importance for understanding patients' experiences, qualitative research remains peripheral in medical curricula, often reduced to merely a title in statistics-dominated research courses. We observed that such courses are generally conducted by instructors with a statistical or quantitative orientation. All of these seem to implicitly relegate the visibility and importance of qualitative research to a secondary position. It is possible to state that a similar problem exists at the postgraduate level. Based on our experience—working in one of the most established medical schools in Turkey—qualitative research methodology remains insufficiently integrated into medical education, except in disciplines that have a relatively strong orientation toward the social dimensions of health. For instance, in our unit, a course on qualitative research methodology was introduced in 2023. However, bioethics remains the only well-established discipline within medicine in Turkey that primarily focuses on meaning and understanding, similar to the human sciences in medicine. One of the authors of this article taught this course, and his experience highlighted the inadequacy of qualitative research training in medical and health sciences curricula. Unsurprisingly, almost all postgraduate students in our courses—primarily from health sciences backgrounds—were unfamiliar with qualitative methodology. Furthermore, certain key concepts in qualitative research proved challenging for students to grasp. The primary obstacle was the pervasive influence of the established biomedical and statistical paradigm, which required continuous reminders to reorient students' perspectives. Even now, we encounter difficulties stemming from the entrenched statistical ethos when guiding students through qualitative research.

We are pleased to see a growing interest in qualitative research in Turkey as well as globally. This is evident in the increasing number of publications in the field. However, as mentioned earlier, the increase in publications on a methodology that is still insufficiently integrated into curricula has

important epistemological and ethical implications that warrant discussion. Our concern stems from observations and experiences in collaborative research with educators and other researchers. One key issue is that some individuals, perceiving themselves as insufficiently proficient in statistics or mathematics, view qualitative research as an easier alternative. To some extent, this reflects a misuse of qualitative research's ontological and epistemological foundations—particularly its focus on life experiences and the subjective worlds of research participants. Given the ontological, epistemological, and ethical significance of qualitative research, we consider this a serious ethical concern. This issue becomes even more critical when we recognize the substantial contributions and ongoing discussions surrounding qualitative research quality. When we ask a researcher conducting qualitative research why they chose this methodology, we often receive responses such as, "I don't know statistics, so at least I can do this [qualitative research]." Unfortunately, when we inquire whether they have received formal training in qualitative research, we frequently struggle to receive an affirmative answer.

This experience highlights two key issues. First, statistical data remains the dominant and more prestigious form of evidence, particularly in medicine and health sciences. While we do not argue that statistical methods lack value, qualitative research continues to be perceived as secondary and is often not treated as a field requiring rigorous training. This, in turn, raises concerns about both the quality of qualitative research and the competence of researchers engaging in it. From our perspective, this situation makes scientific competence—one of the fundamental requirements of research ethics—both questionable and problematic from the outset. However, we also want to emphasize that our critique is not intended to unfairly target academic units or educators providing qualitative research training. Nevertheless, when we compare the training we receive in Turkey, particularly in the health sciences, with the training available in countries where qualitative research is more established, we must acknowledge that qualitative education in Turkey tends to maintain a discourse that is ontologically and epistemologically closer to the post-positivist end of the spec-

trum. In this respect, it is possible to state that qualitative research is not addressed comprehensively within the spectrum of small q-big Q, and that the ontological, epistemological philosophical framework toward the end close to the big Q concept or interpretation is not sufficiently established(28). This may be significantly related to the dominant paradigmatic view in the field of health sciences(29). In conclusion, we would like to add that the ontological, epistemological, and ethical meaning of qualitative research in medicine has not been sufficiently discussed at the theoretical and philosophical levels. However, in fields such as medicine, where researchers from different disciplines and paradigms come together, it is important to be familiar with both our own paradigm and the approaches of the researchers we work with, even at a basic level(30). Yes, if we look at the field of health sciences in Turkey from a purely quantitative and practical perspective, we can say that a significant number of qualitative studies are being conducted. However, we observe that issues such as the meaning, foundations and value of qualitative research in different medical contexts - such as education, understanding experiences and clinical outcomes - have not been adequately addressed. In this regard, we would like to emphasize that existing training programs, where they exist, are largely limited to the practical aspects of conducting and publishing research, rather than encouraging a deeper engagement with its theoretical and methodological dimensions.

The predominantly negative experiential content discussed in this section is closely linked to the themes explored in the following two sections. While it is not our intention to suggest that every researcher must become a methodological expert, we believe that the lack of awareness regarding even basic concepts and the distinctive epistemological characteristics of qualitative research represents a significant issue in Turkey. This gap in understanding is directly connected to challenges encountered in research ethics committees and publication processes, which will be discussed later. However, this issue is not confined to Turkey; similar challenges can be observed in the publication process globally, including during editorial and peer-review evaluations. Moreover, as researchers who have lived these processes may

eventually serve on research ethics committees, become journal editors, or act as reviewers, the medical field needs to cultivate researchers and students who possess a solid grasp of their discipline and are well-acquainted with diverse methodological approaches(30,31).

Insights from inside the ethics committee: There was a lack of methodological awareness and relevant problems

Our experiences as both ethics committee members and applicants reveal that qualitative research applications in medicine are extremely limited compared to quantitative research and confined to certain fields. In addition, regarding qualitative and quantitative research categories, it is possible to say that research ethics committees treat many survey research that actually have a qualitative character as classical quantitative research. We believe that this situation is closely related to the established biomedical and statistical research paradigm. Although limited, qualitative research applications are also affected by this paradigmatic influence in various ways.

Reflecting on our applications, qualitative research either receives cursory approval or faces quantitatively driven critiques that force conformity to biomedical and statistical discourse. Both tendencies, we argue, present ethical concerns. The root of this issue lies in the composition of research ethics committees, which are predominantly oriented toward biomedical and statistical paradigms. Even when committee members possess some familiarity with qualitative research, they often evaluate it through a quantitative lens. As a result, ethical evaluations tend to emphasize concepts such as sampling, validity, and reliability—aligning with the expectations of statistics-based biomedical models. However, despite this methodological emphasis, the ethical dimensions of qualitative research and the researcher's relationship with participants remain relatively underexplored. In other words, prioritizing statistically driven evaluations can lead to formalistic and mechanistic assessments that overlook other ethically significant aspects. To some extent, this also contributes to the tendency for ethics committees to grant easy approval to qualitative research that is framed within a quantitative paradigm.

These problems largely stem from an insufficient understanding of qualitative research and its significance within medicine. The ontological, epistemological, and ethical dimensions of qualitative research remain poorly understood by researchers and ethics committee members alike. Two key situations illustrate this issue. First, based on our experience with ethics committees and research applications, we have noticed that researchers and ethics committee members from various health sciences disciplines often fail to situate qualitative research within a broad paradigmatic continuum. In practice, even when an ethics committee member claims to have a qualitative orientation, they frequently evaluate qualitative research as a singular methodological approach rather than recognizing its diverse paradigmatic orientations. Consequently, assessments, suggestions, and critiques tend to align predominantly with a post-positivist (small q) perspective. Second, this issue may also be influenced by ethics committee standards and review protocols. For instance, in nearly all of the ethics committees we have worked with or applied to, researchers are required to numerically declare their sample size in application forms. Such formal requirements may contribute to reinforcing a post-positivist framing of qualitative research. More broadly, the role of standardization, checklists, and guidelines in qualitative research remains a topic of ongoing debate worldwide(32). In this context, we can say that research ethics committees need guidelines that take qualitative research methodology into account and define it in detail instead of quantitative and statistically oriented application standards. This may provide an opportunity not only for ethics committee members and researchers to reflect on the nature of their research. In this context, it is essential to take into account the pluralistic orientation of qualitative research, which is not absolutist and allows flexibility, which some researchers rightly and persistently emphasize, in order not to fall into a new reductionism(32).

In the previous section, we highlighted that the awareness and competence of individuals conducting qualitative research regarding the nature of their work constitute a distinct problem category. We observe a clear reflection of this issue within research ethics committees. Researchers

must demonstrate methodological congruence; in other words, they should have a clear understanding of what they are doing and writing(29). Unfortunately, one of the challenges we encounter as ethics committee members is that when researchers receive feedback or negative criticism from the committee, they often struggle to defend their methodological position adequately. Even when we believe they are justified in their approach, they frequently remain passive in their responses. One possible reason for this is the perceived dominance of the quantitatively oriented biomedical paradigm, which may leave researchers feeling powerless in challenging the prevailing standards. However, in our view, another key issue is that many researchers have yet to reach what Braun and Clarke describe as the “knowing researcher” stage—a critical level of methodological competence(31). Additionally, it is not uncommon for researchers to adapt their approach to align with small q qualitative research or even quantitative methodologies due to the pressures of the “publish or perish” culture(33). This tendency to conform further entrenches the statistically oriented paradigm and reinforces existing ethics committee review processes. We argue that when researchers develop a stronger understanding of their methodology and confidently articulate their position, they may also encourage research ethics committees to critically reflect on their own evaluative frameworks(34-36).

Across all scientific disciplines in Turkey, the establishment of research ethics committees has been primarily shaped by legal regulations in the health sciences. Although regulatory changes in this field are frequent, legally binding clinical research ethics committees inevitably serve as a model when determining the principles for other ethics committees. We highlight this point because clinical research ethics committees operate within a predominantly biomedical and statistically oriented framework(37).

However, the role of research ethics committees extends beyond merely evaluating research protocols for approval. They also play a crucial role in promoting education, providing guidance, and shaping policies on research and publication ethics. Studies indicate that persistent challenges in this area suggest the need for research ethics com-

mittees to critically reassess their training, advisory functions, and policy development processes. In our view, it is essential for research ethics committees to adopt a comprehensive evaluative framework that considers the broader implications of their decisions. This requires committee members to develop the expertise necessary to engage with diverse research methodologies, contribute to their advancement, and intervene when necessary. Given the complexity of human understanding—an aspect that cannot be reduced to purely biological applications—we argue that research ethics committees should approach qualitative methodologies with a perspective that is both virtuous and flexible, prioritizing the depth of human experience in their assessments(3,9,14).

A disappointment: Epistemic injustice against qualitative research and the researcher; even in the field of bioethics

In the field of medicine, qualitative research continues to face challenges in gaining recognition, as many medical journals still do not prioritize it. Even when qualitative studies are included in the review processes of medical journals, they are frequently evaluated through a quantitative or post-positivist lens (32). Consequently, the experiences we discuss here will likely resonate with many qualitative researchers. As scholars engaged in both qualitative research and research ethics, we frequently encounter similar challenges. However, we believe that the core of our argument lies in the unique role of qualitative research in fostering an understanding of human experiences. Even in disciplines familiar with qualitative methods, a lack of reflexivity still poses challenges for researchers.

Bioethics, a field in which we conduct academic studies, shares a close relationship with medical humanities. The pursuit of understanding human beings is a fundamental aim of both disciplines, making qualitative research an indispensable tool for exploring and interpreting these fields(27). Although bioethics and ethics are often considered more theoretically driven disciplines, there has been a growing emphasis on empirical studies, particularly in bioethics. This shift has allowed for deeper exploration of individuals' values, decision-making processes, lived experiences, and their ethical and normative dimensions(38). Some scholars

have even referred to this trend as the “empirical turn” in bioethics(39,40). Given the nature of bioethics, qualitative research constitutes a significant portion of empirical studies in the field(41). In this context, it is reasonable to expect that journals specializing in bioethics and medical humanities would be well-versed in evaluating qualitative research. However, as we will discuss further, epistemic injustices against qualitative research and researchers persist even within these disciplines, raising important concerns about the way qualitative methodologies are assessed and valued.

However, as the title of this section suggests, we regret to acknowledge that even in leading journals in the field of bioethics and medical ethics, qualitative research articles are not uncommonly rejected based on post-positivist criteria during editorial and peer-review processes. To illustrate this, we would like to briefly share a recent experience with one of our articles that centered on “participant experiences”—ironically focusing on research ethics. We believe this case serves as a valuable example for understanding the epistemic position of qualitative research and its researchers. Our article was evaluated by two reviewers. One reviewer demonstrated a strong command of qualitative methodology, offering feedback and critiques that aligned with qualitative research principles. The second reviewer, however, approached the article from a distinctly post-positivist stance, raising concerns about generalizability and sampling that demonstrated a misunderstanding of qualitative research principles, including purposive sampling. While we could have addressed these critiques by clarifying the nuances of our methodology, we were denied the opportunity to do so. So, what happened? The editor rejected the article outright based on the quantitatively oriented reviewer's concerns, despite the qualitative-familiar reviewer recommending only revisions. The editor deemed the paper ‘unfixable’ due to supposed scientific method deficiencies. What makes this case particularly striking is that it took place in a well-regarded journal in the field of bioethics and medical ethics—a field where qualitative methodologies should, in principle, be recognized as essential. Following this decision, we mailed the journal to express our concerns regarding the editorial and review process,

highlighting the established role of qualitative research in bioethics and the ethical implications of dismissing qualitative methodologies based on positivist paradigms. Our motivation for doing so was our deep concern that qualitative research was being constrained by entrenched epistemological barriers, even within an ethics journal. We argue that this is not only a methodological issue but also an ethical one. These obstacles reflect a reductionist perspective that risks dismissing the lived experiences of research participants—an issue that extends beyond individual editorial decisions and speaks to broader systemic biases. Even in disciplines like bioethics, where understanding human experience is a fundamental aim, reductionist tendencies can reemerge if not actively resisted (32). Furthermore, we argue that this reductionism represents a clear case of epistemic injustice against qualitative research and its participants. On one hand, our qualitative methodology was treated as subordinate to positivist approaches—an instance of hermeneutical injustice (26). On the other hand, we were denied the opportunity to defend our methodological choices, constituting testimonial injustice. As Fricker correctly emphasizes, epistemic injustice is a pervasive issue across different disciplines, and at its core, it is an ethical problem. Overcoming such injustice requires not only intellectual and ethical virtues on an individual level but also a concerted effort to challenge and reform entrenched institutional biases(26).

At this point, it is essential to cultivate reflexivity regarding the ways in which the dominant positivist and post-positivist orientation in academia—especially in research ethics committees, editorial boards, and peer review—may inadvertently disadvantage qualitative research. In this context, we argue that reflexivity serves as both an ethically and intellectually meaningful starting point, functioning as a virtue that can help address issues such as epistemic injustice. Moreover, reflexivity can also be seen as a crucial tool for researchers to identify and develop their competencies in areas where they may lack expertise. Developing a deeper philosophical understanding of one's field, as well as the interdisciplinary areas it interacts with, is essential for fostering more informed and equitable evaluations(30).

Another concept closely linked to reflexivity and

worth considering in this discussion is epistemic humility. Epistemic humility entails an awareness that our engagement with knowledge and methodology is inherently fallible, and that we must remain open to the possibility of error(42). By embracing epistemic humility, scholars, ethics committee members, and reviewers can foster a more inclusive and reflective approach to diverse research methodologies, ultimately contributing to a more just and balanced academic landscape.

Know thyself! Reflexivity as an ethical virtue

Our experiences highlight how ethics in qualitative research extends beyond procedural compliance with ethics committees, challenging principle-based approaches in favor of more nuanced ethical engagement(43). We propose reflexivity—a practice central to qualitative research—should be recognized as an ethical virtue embodying the philosophical imperative: “Know thyself!” This concept is particularly relevant because, in our experience, a lack of reflexivity—ranging from individual researchers to institutional bodies such as journals and ethics committees—constitutes the most fundamental barrier to mutual understanding and intellectual development. We argue that this deficiency is a key inhibitor of epistemic openness and progress.

A qualitative researcher's awareness of their own ontological and epistemological position carries ethical implications and consequences. Thus, cultivating philosophical self-awareness among qualitative researchers is crucial. The first step in this process is foundational knowledge of qualitative research and its underlying principles—an issue we have identified as a major obstacle. This gap in understanding must be addressed to enable epistemological reflection, which, in turn, allows for deeper reflexivity throughout the research process. Therefore, it is imperative to embed qualitative research within the intellectual frameworks of scholars in medicine and health sciences, ensuring that its ontological and epistemological significance is properly acknowledged(21,30).

Reflexivity should also be emphasized as an ethical virtue for those in evaluative positions—ethics committee members, editors, and reviewers—both at an institutional level and as individuals.

Some scholars have underscored the importance of collective reflection, particularly in research groups composed of multiple researchers⁽⁴⁴⁾. We believe that this need for collective reflexivity extends to research ethics committees, which are expected to integrate diverse disciplinary perspectives and facilitate comprehensive epistemological evaluations. However, based on our experiences, we observe that biomedical and statistical paradigms continue to dominate these evaluative structures—either explicitly or implicitly—rather than fostering an environment that encourages critical reflection. Discourses emphasizing intellectual reflexivity must become embedded within the philosophical foundations and operational practices of research ethics committees.

We contend that fostering reflexivity in evaluative structures could promote greater epistemic equality, granting qualitative researchers a stronger voice when engaging with research ethics committees, editors, and reviewers. However, for research ethics committees and editorial boards to engage meaningfully in reflection, they must possess an informed understanding of diverse research paradigms. In fact, this expectation should be considered an essential virtue for those in positions of evaluative authority⁽⁴⁵⁾. Our experience suggests that these virtues must be actively and repeatedly reinforced. In this regard, we argue that a reflexive attitude serves as an essential and continuous ethical reminder for all those involved in the academic evaluation process.

Conclusion

Our experiences have revealed systemic challenges in the recognition and evaluation of qualitative research within medical contexts. These challenges reflect deeper ontological, epistemological, and ethical tensions within contemporary medical research culture. Our analysis highlights how the marginalization of qualitative research represents not merely a methodological preference but rather an epistemic injustice that has significant implications for medical knowledge production and practice.

The experiences shared in this paper demonstrate that even in fields traditionally receptive to qualitative approaches, such as bioethics and medical

humanities, researchers face persistent barriers rooted in positivist and post-positivist paradigms. This situation is particularly concerning in the Turkish context, where qualitative research education remains limited and research ethics committees often operate with evaluation frameworks better suited to quantitative methodologies. The irony of experiencing epistemic injustice in bioethics journals—a field that should be particularly attuned to issues of justice and understanding human experience—underlines the pervasive nature of these challenges.

Our analysis suggests that several critical areas require attention. First, there is an urgent need to strengthen qualitative research education within medical curricula to ensure that researchers develop not only methodological skills but also a deeper understanding of qualitative research's philosophical foundations. Second, research ethics committees should develop more nuanced evaluation frameworks that recognize the distinct characteristics and value of qualitative methodologies. Third, the academic publishing ecosystem must become more reflexive about its own biases and inclusive of diverse methodological approaches. The field of medicine continues to grapple with the complexities of human health and illness, and the need for diverse methodologies has become increasingly clear. Our experience suggests that resolving the tensions between ethics and science in qualitative research requires not only procedural changes but also a fundamental shift in how we conceptualize and value different forms of knowledge in medicine. Only through such transformation can we hope to develop a more inclusive and ethical research environment that serves both the scientific and humanistic aims of medicine.

We propose reflexivity as both a methodological requirement and ethical virtue that can help address these challenges. This approach requires all stakeholders—researchers, ethics committee members, and journal editors—to critically examine their own philosophical assumptions and biases. In medicine, where understanding human experience is crucial for effective care, the ability to move between different paradigms and appreciate diverse forms of knowledge production is essential.

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DILEMAS ÉTICOS Y DESAFÍOS EN LA SOCIEDAD DIGITAL: UN ENFOQUE MULTIDISCIPLINARIO SOBRE LA CIBERADICCIÓN Y LA REGULACIÓN TECNOLÓGICA

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Resumen: Este manuscrito examina la complejidad creciente de la ciberadicción, un fenómeno cada vez más normalizado socialmente pero aun insuficientemente investigado y regulado. La ciberadicción comparte rasgos con otras formas de dependencia, al surgir de experiencias de placer inmediato que pueden transformarse en necesidad. Desde una perspectiva multidisciplinaria, el texto analiza factores históricos, familiares, neurobiológicos y sociotécnicos que contribuyen a su desarrollo, destacando el papel del placer digital y de las arquitecturas tecnológicas diseñadas para captar y retener la atención del usuario. Asimismo, se abordan los dilemas éticos asociados a su conceptualización, interrogando si la ciberadicción constituye un trastorno autónomo o una manifestación de transformaciones más amplias en la relación humana con la tecnología. El manuscrito profundiza en tensiones vinculadas a autonomía, vulnerabilidad, responsabilidad corporativa y privacidad, proponiendo un enfoque que reconoce la complejidad moral del ecosistema digital contemporáneo. En conjunto, el trabajo articula aportes de la neurociencia, la psicología, la bioética y los estudios sociotécnicos para ofrecer una comprensión integrada del fenómeno. Se plantea la necesidad de equilibrar los beneficios del uso intensivo de tecnologías con los riesgos asociados, promoviendo prácticas que favorezcan un uso saludable, crítico y éticamente responsable. En síntesis, se sitúa la ciberadicción como un desafío emergente de la era digital.

Palabras clave: ciberadicción, dilemas éticos, autonomía digital, regulación tecnológica, dependencia tecnológica

Ethical dilemmas and challenges in digital society: a multidisciplinary approach to cyberaddiction and technological regulation

Abstract: This manuscript examines the growing complexity of cyberaddiction, a phenomenon that is becoming increasingly socially normalized but still insufficiently researched and regulated. Cyberaddiction shares traits with other forms of dependency, arising from experiences of immediate pleasure that can become a necessity. From a multidisciplinary perspective, the text analyzes historical, familial, neurobiological, and sociotechnical factors that contribute to its development, highlighting the role of digital pleasure and technological architectures designed to capture and retain the user's attention. It also addresses the ethical dilemmas associated with its conceptualization, questioning whether cyberaddiction constitutes an autonomous disorder or a manifestation of broader transformations in the human relationship with technology. The manuscript delves into tensions related to autonomy, vulnerability, corporate responsibility, and privacy, proposing an approach that recognizes the moral complexity of the contemporary digital ecosystem. Overall, the work brings together contributions from neuroscience, psychology, bioethics, and socio-technical studies to offer an integrated understanding of the phenomenon. It raises the need to balance the benefits of intensive use of technologies with the associated risks, promoting practices that favor healthy, critical, and ethically responsible use. In summary, cyber addiction is positioned as an emerging challenge of the digital age.

Keywords: cyberaddiction, ethical dilemmas, digital autonomy, technological regulation, technological dependence

Dilemas éticos e desafios na sociedade digital: um enfoque multidisciplinar sobre a dependência digital e a regulação tecnológica

Resumo: Esse manuscrito aborda a crescente complexidade da dependência digital, um fenômeno que compartilha características com outras formas de dependência, derivada de um prazer imediato que se transforma em necessidade. Através de uma perspectiva multidisciplinar, o texto explora fatores históricos, familiares e neurológicos que contribuem para este fenômeno, destacando o papel central do prazer digital. Além disso, levanta dilemas éticos ao debater se a dependência digital deve ser considerada um transtorno em si mesma ou uma manifestação de uma mudança humana. O presente trabalho amplia essa discussão ao incorporar uma articulação mais explícita entre neurociência, psicologia, bioética e estudos sociotécnicos, permitindo compreender a dependência digital como um fenômeno emergente próprio de uma ecologia digital desenhada para captar e reter a atenção do usuário. Além disso, aprofunda-se nas tensões éticas vinculadas a autonomia, vulnerabilidade, responsabilidade corporativa e privacidade, superando o uso generalizado e impreciso do conceito "dilema" e adotando um enfoque analítico que reconhece a complexidade moral do ecossistema digital contemporâneo. É proposta uma abordagem integradora orientada a equilibrar os benefícios e riscos do uso intensivo de tecnologias, promovendo práticas que favorecem um uso saudável e eticamente responsável.

Palavras chave: dependência digital, dilemas éticos, autonomia digital, regulação tecnológica, dependência tecnológica

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Introducción

Este manuscrito surge de una reflexión multidisciplinaria orientada a problematizar la creciente complejidad de la ciberadicción, con el propósito de dialogar, deconstruir y reconstruir los conocimientos existentes sobre este fenómeno. Aunque su presencia es cada vez más visible, continúa siendo escasamente abordada tanto en la investigación como en la formulación de políticas públicas. En este marco, se vuelve necesario avanzar hacia un enfoque sistémico que articule perspectivas conceptuales capaces de superar aproximaciones fragmentadas o meramente descriptivas.

Actualmente, la ciberadicción se configura como una de las formas de dependencia más normalizadas socialmente. Su presencia es ubicua y, lejos de ser cuestionada, suele ser promovida en entornos familiares, educativos y en eventos de alcance nacional e internacional. Esta naturalización dificulta la identificación de riesgos y la implementación de estrategias preventivas y terapéuticas. La hiperconectividad, la economía de la atención y el diseño persuasivo de las plataformas conforman un ecosistema sociotécnico que estructura la vida cotidiana.

Desde una perspectiva multidisciplinaria, este estudio examina la ciberadicción a partir de conceptos clave que permiten profundizar en su comprensión y, a la vez, orientar propuestas para el ámbito de las políticas públicas. La multidisciplinarietà no se limita a la coexistencia de enfoques, sino que exige integrar neurociencia, psicología, bioética y estudios sociotécnicos para explicar tanto los mecanismos de compulsión como los condicionamientos culturales y normativos que moldean el comportamiento.

Toda adicción tiene su origen en un apego, un afecto o un hábito que puede transformarse en dependencia. Según la Real Academia Española(1), el apego se entiende como una inclinación hacia alguien o algo, vinculada a términos como afecto, aprecio o interés. En el contexto digital, estos vínculos se canalizan hacia dispositivos y plataformas que median la experiencia humana, configurando nuevas formas de apego tecnológico.

La formación de apegos implica experiencias físicas y emocionales asociadas al placer generado por una

actividad o conducta. Esta asociación refuerza la repetición y, en determinados contextos, puede derivar en un proceso adictivo. En el ámbito digital, este proceso se intensifica debido a refuerzos inmediatos y adaptativos, orientados algorítmicamente a maximizar la repetición de la conducta.

Mate(2) señala que el apego es un impulso instintivo destinado para preservar la cercanía con otros, fundamental para el desarrollo humano. A partir de esta definición, la ciberadicción puede entenderse como un fenómeno complejo influido por factores históricos, familiares, físicos y neurológicos que predisponen a la formación de apegos hacia situaciones, comportamientos u objetos, como ocurre con las tecnologías digitales. La accesibilidad permanente y la gratificación inmediata facilitan la transición desde el uso recreativo hacia patrones compulsivos.

Este apego atraviesa generaciones y contextos socioeconómicos. Para que evolucione hacia una adicción, debe existir un entorno que genere placer y bienestar difícil de encontrar fuera del circuito digital, reforzando la dependencia. Así, la ciberadicción emerge de la interacción entre predisposiciones individuales y arquitecturas tecnológicas diseñadas para estimular conductas repetitivas.

El manuscrito reflexiona sobre la transición del apego hacia la adicción, momento en que el vínculo se convierte en un trastorno que afecta a la persona y su entorno. En este contexto, se examina el rol de la ética, la bioética y la moral, así como la necesidad de analizar perfiles socio epidemiológicos y posibles tratamientos a nivel micro y macro.

El placer constituye un elemento central en esta transición. Se trata de una experiencia compleja, influida por factores biológicos y psicológicos, asociada a la activación de los circuitos mesocorticolímbicos y a la liberación de neurotransmisores como dopamina y endorfina(3). Estas dinámicas permiten explicar cómo la interacción con dispositivos digitales reproduce patrones de refuerzo propios de las adicciones conductuales.

Aunque el impulso hacia la satisfacción cumple funciones adaptativas, también puede extenderse a actividades complejas, generando dependencia. En entornos digitales, estas dinámicas se intensifican

por la inmediatez del refuerzo y la disponibilidad permanente de estímulos. Como señala Valdebenito-Herrera(4), el ser humano busca satisfacer necesidades básicas antes de desarrollar estructuras cognitivas avanzadas, lo que explica la centralidad del placer en la vida cotidiana.

El placer también opera en contextos emocionales y sociales, contribuyendo a la regulación afectiva. Incluso experiencias negativas, como la tristeza evocada por la música, pueden generar placer si favorecen la gestión emocional(5). Sin embargo, cuando se asocia a conductas adictivas, afecta la capacidad de autocontrol y la flexibilidad mental(6). En este sentido, la ciberadicción puede entenderse como una expresión contemporánea de sistemas de recompensa modulados por arquitecturas digitales altamente personalizadas.

A pesar de los avances en salud y de los Objetivos de Desarrollo Sostenible(7), la promoción del placer no ha sido considerada una estrategia preventiva. Los marcos regulatorios privilegian prácticas saludables estructuradas, sin reconocer que el placer mediado tecnológicamente puede convertirse en una vía crítica hacia la compulsión.

Este manuscrito también aborda el concepto de *trouble-disorder*(8), que distingue entre problema y trastorno, desplazando el foco desde lo social hacia la experiencia individual. En el ámbito digital, esta distinción permite reconocer que ciertos usos problemáticos no derivan de disfunciones previas, sino de la interacción prolongada con sistemas diseñados para promover la permanencia del usuario.

Siguiendo a Jaremka et al.(9), *trouble* abarca dificultades que afectan a individuos y grupos en distintos contextos, incluyendo el estrés, la ansiedad y la depresión. En la ciberadicción, estas manifestaciones pueden estar mediadas por la exposición constante a estímulos digitales y la sobrecarga informativa.

Desde la filosofía social, Butler(10,11) amplía el concepto de *trouble* al cuestionar normas tradicionales, otorgándole un valor liberador. Trasladado al ámbito tecnológico, este enfoque permite examinar cómo las prácticas digitales reconfiguran la agencia, la socialización y el consumo, generando oportunidades y vulnerabilidades.

En neurociencia, *trouble* también refiere a dificultades asociadas a trastornos cerebrales, como en el autismo, donde alteraciones sensoriales y motoras afectan la interacción social(12). Integrar esta perspectiva evidencia que las respuestas neurobiológicas al entorno digital varían entre individuos, generando niveles diferenciados de vulnerabilidad.

Desde una perspectiva neurofisiológica, la adicción es un proceso que evoluciona hacia la compulsión, influido por aprendizajes pavlovianos e instrumentales. Este proceso implica un desplazamiento del control neuronal desde la corteza prefrontal hacia el cuerpo estriado, acompañado de neuroplasticidad asociada al consumo crónico(13). La adicción puede entenderse como un ciclo de disregulación de los sistemas de recompensa, generando un estado alostático caracterizado por alteraciones crónicas(14). Diversas teorías abordan las respuestas hedónicas, el aprendizaje aberrante y el control de impulsos(15).

La impulsividad se vincula estrechamente con la vulnerabilidad a la adicción(16). La neuroplasticidad en el circuito corticoestriatal desempeña un papel crucial, ya que el consumo crónico interfiere con el control prefrontal(17). Los recuerdos inducidos por drogas pueden contribuir a la recaída al manipular la plasticidad sináptica, mientras que la exposición prolongada altera irreversiblemente los circuitos motivacionales(18,19). Los sistemas cerebrales del estrés, como el factor liberador de corticotropina (CRF) y la noradrenalina, también son fundamentales en la dependencia(20).

Mate(2) subraya que comprender la adicción requiere preguntarse qué alivio busca el adicto. La experiencia literaria de Thomas De Quincey ilustra cómo las drogas pueden ofrecer una sensación de claridad y alivio emocional. Desde esta perspectiva, la adicción surge en un terreno propicio marcado por el dolor emocional y la necesidad de evitar el vacío mental(2).

En la adicción tecnológica, el flujo constante de datos elimina los vacíos y transforma la información en conocimiento(21), aunque rara vez en entendimiento o sabiduría. Este manuscrito invita a reflexionar sobre este *trouble-disorder* en el contexto digital contemporáneo.

Dilemas éticos en la ciberadicción

La ciberadicción se define como una dependencia patológica del uso del ciberespacio y las tecnologías digitales, considerada una adicción no química con características propias en términos de nosología, etiología y patogénesis, lo que demanda prevención, tratamiento y corrección psicológica(22). Esta adicción se manifiesta en diversas formas, como la adicción a Internet, los videojuegos, el uso excesivo de gadgets, la ciber comunicación y el cibersexo(23). Investigaciones han mostrado que la ciberadicción comparte factores de riesgo con otras adicciones conductuales y puede estar vinculada con comportamientos problemáticos, como la agresión cibernética y la violencia en el ámbito digital(24,25). Además, se ha identificado como un factor de vulnerabilidad en adolescentes para ser víctimas de ciberacoso, especialmente cuando existe una falta de apoyo familiar y social(26).

En este contexto, uno de los dilemas abordados en este trabajo es si la ciberadicción debe considerarse un *trouble-disorder* o trastorno. De ser así, ¿debería ser identificada, cuantificada y tratada de manera adecuada? Al revisar la definición de problema, las actividades o comportamientos considerados trastornos suelen definirse como tal porque impiden el desarrollo pleno de la vida individual y colectiva. Sin embargo, en el caso de la ciberadicción, y más aún en el contexto económico, político y bélico actual, esa adicción no parece obstaculizar la funcionalidad ni el desarrollo personal. Por el contrario, la ciberadicción puede apoyar al ser humano al satisfacer sus inquietudes, responder a preguntas y brindar afecto a través de palabras y consejos, y ciertamente fomenta una mayor capacidad de desempeño. En consecuencia, cabe preguntarse si la ciberadicción debe ser identificada, diagnosticada, pronosticada y tratada.

Otro dilema que surge de esta reflexión es la naturaleza de los seres humanos, es decir, ¿qué tipo de *Homo sapiens sapiens*(4) somos o si estamos en un proceso de involución hacia un *Homo habilis*, en el que la rápida adquisición de información ya no constituye un desafío, sino el saber utilizar y manejar de manera hábil las herramientas tecnológicas?

A pesar de la relevancia de estos cuestionamientos, la definición de ciberadicción sigue siendo un tema

controvertido. Algunos autores la equiparan con adicciones conductuales como la ludopatía(27), mientras que otros sostienen que el uso excesivo de tecnología no necesariamente sigue los mismos patrones de los trastornos relacionados con sustancias(28). Esta falta de consenso se refleja en los criterios heterogéneos para determinar qué comportamientos son patológicos, así como en la ausencia de un diagnóstico consolidado en el DSM-5, que solo menciona de manera provisional el *Internet Gaming Disorder*(29).

El debate también abarca la cuestión de si la ciberadicción es un trastorno en sí misma o si simplemente es una manifestación de otros problemas subyacentes, como déficits de autocontrol o condiciones psicosociales adversas(30). Desde una perspectiva ética, esta indefinición plantea dilemas sobre el riesgo de sobrediagnóstico y estigmatización, o, por el contrario, de subestimación de problemas reales que afectan a personas vulnerables(31).

Uno de los dilemas más relevantes en el tratamiento de la ciberadicción es el equilibrio entre la autonomía individual y la necesidad de intervención profesional o familiar. Si bien algunas personas reconocen su problema y buscan tratamiento, otras no perciben su comportamiento como una adicción o minimizan sus efectos negativos(27). Esto plantea la cuestión de hasta qué punto es ético intervenir de manera coercitiva para proteger la salud de alguien que no solicita ayuda.

Cuando se trata de menores de edad, el dilema se torna aún más complejo. Niños y adolescentes se encuentran en una etapa crucial de desarrollo cognitivo y emocional, lo que puede dificultar su capacidad para evaluar los riesgos del comportamiento en línea. Los padres y educadores deben decidir si imponer límites estrictos, como bloquear redes sociales o videojuegos, es una medida justificada, o si, por el contrario, podría vulnerar el derecho de los menores a explorar y aprender digitalmente(32). Además, algunas investigaciones sugieren que intervenciones autoritarias pueden generar una resistencia al tratamiento y debilitar la confianza entre padres e hijos(31).

En ciertos casos, la ciberadicción está vinculada a otros trastornos, como ansiedad y depresión, lo que aumenta el riesgo de conductas suicidas(33).

Esto obliga a los profesionales a adoptar enfoques terapéuticos que respeten la autonomía del individuo, pero que también sean efectivos para prevenir daños mayores.

El monitoreo de la actividad digital es una herramienta clave para evaluar la gravedad de la ciberadicción, pero también genera dilemas sobre la privacidad y la protección de datos. Las terapias en línea y las aplicaciones de control parental pueden requerir acceso a información sensible, como el historial de navegación y las redes de contacto. Sin embargo, la supervisión excesiva puede percibirse como una invasión a la privacidad, especialmente si no existe un consentimiento informado claro que defina sus alcances y limitaciones(34).

Desde un enfoque bioético, el principio de no maleficencia debe equilibrarse con el de beneficencia. La recopilación de ciertos datos sólo debe justificarse si es estrictamente necesaria para un tratamiento efectivo, respetando los derechos de confidencialidad del paciente(32). No obstante, el manejo de estos datos por parte de terceros, como empresas tecnológicas, introduce riesgos adicionales, ya que podrían ser utilizados con fines comerciales o de vigilancia, lo que resalta la necesidad de regulaciones estrictas en protección de datos(35).

En cuanto a los menores, el control parental puede derivar en un monitoreo excesivo que afecte la confianza y el desarrollo de su autonomía digital(34). Por lo tanto, es crucial que cualquier estrategia de supervisión respete la privacidad de los menores mientras los protege de los peligros asociados con el uso excesivo de la tecnología.

Un dilema adicional es la paradoja del tratamiento digital. Muchas intervenciones contra la ciberadicción dependen de herramientas tecnológicas, como aplicaciones de autoayuda, terapia en línea e incluso programas de realidad virtual. Aunque estos recursos facilitan el acceso a la atención psicológica, también plantean la contradicción de depender de la misma tecnología que se busca regular(36).

Si bien la tele terapia permite superar barreras geográficas y brinda apoyo continuo(37), también puede reforzar el uso compulsivo de pantallas, especialmente entre los pacientes más jóvenes. Además, la proliferación de plataformas comerciales que

ofrecen tratamientos en línea sin una regulación adecuada genera preocupaciones sobre la calidad y la ética de estos servicios, ya que podrían priorizar el lucro sobre la efectividad terapéutica(30).

Etiquetar a una persona como ciberadicta conlleva implicaciones sociales y emocionales significativas. El término “adicción” tiene una connotación negativa que puede reforzar la discriminación, especialmente en un mundo donde la hiperconectividad se percibe como un rasgo de productividad y modernidad(38), lo que dificulta la distinción clara entre un uso intensivo y un uso problemático de la tecnología.

La industria tecnológica también desempeña un papel crucial en este fenómeno. Las plataformas digitales emplean estrategias de gamificación y algoritmos diseñados para maximizar el tiempo de uso, fomentando así conductas adictivas(39). Desde una perspectiva ética, es necesario debatir hasta qué punto estas empresas deberían asumir responsabilidad en la mitigación de la ciberadicción, ya sea a través de mecanismos de autorregulación o mediante regulaciones estatales más estrictas.

En definitiva, la ciberadicción puede entenderse como un problema complejo que involucra factores clínicos, tecnológicos y sociales. Para abordarlo eficazmente, es necesario encontrar un equilibrio entre la autonomía individual, la prevención del abuso digital y la intervención terapéutica. La privacidad, el derecho a la autodeterminación y la responsabilidad de las corporaciones tecnológicas son temas clave en este debate. Solo a través de un enfoque multidimensional se podrán mitigar los riesgos de la ciberadicción y promover un uso saludable de las tecnologías digitales.

Desafíos éticos en la ciberadicción

El fenómeno de la ciberadicción no solo plantea dilemas éticos, sino que también introduce desafíos que deben abordarse desde perspectivas sociales, políticas y tecnológicas, con el fin de desarrollar soluciones que respeten la autonomía individual sin desatender los riesgos asociados. Superar los dilemas previamente expuestos exige estrategias que equilibren prevención, regulación y educación digital, garantizando respuestas efectivas sin vulnerar derechos fundamentales. En este sentido, resulta

imprescindible analizar los desafíos éticos desde una perspectiva estructural que considere tanto las dinámicas de poder involucradas como los impactos sociales y normativos derivados del diseño y la gobernanza tecnológica.

Uno de los principales desafíos éticos consiste en desarrollar criterios diagnósticos consensuados que permitan diferenciar entre el uso intensivo y el uso patológico de la tecnología. La ausencia de consenso en la comunidad científica respecto de qué constituye ciberadicción genera un vacío que puede derivar en diagnósticos inconsistentes y, en consecuencia, en tratamientos inadecuados. Es necesario establecer marcos clínicos basados en evidencia empírica que permitan identificar cuándo el uso excesivo de la tecnología se convierte en una adicción y cuándo responde a factores subyacentes como ansiedad, depresión o exclusión social(27,28,30). Sin criterios claros, existe el riesgo de patologizar comportamientos que podrían formar parte de la adaptación natural a una sociedad digitalizada. Esta problemática se complejiza al observar que trastornos preexistentes, como el trastorno por déficit de atención con hiperactividad (TDAH) y la depresión, pueden aumentar la vulnerabilidad a la ciberadicción, lo que refuerza la necesidad de un diagnóstico integral(40,41).

En segundo lugar, fortalecer la educación digital como herramienta preventiva es fundamental. La ciberadicción se ve agravada por la falta de alfabetización digital crítica, lo que dificulta que las personas, especialmente los jóvenes, desarrollen hábitos de consumo tecnológico saludables. Las estrategias educativas deben ir más allá de la restricción del acceso y centrarse en capacitar a las personas para gestionar su tiempo en línea, identificar signos de dependencia y establecer límites adecuados. Esto requiere un esfuerzo coordinado entre instituciones educativas, familias y organismos gubernamentales para diseñar programas que integren el bienestar digital desde edades tempranas(42,43). La implementación de programas como ConRed ha demostrado ser efectiva en la reducción del ciberacoso y la adicción a Internet, reforzando la importancia de una educación digital estructurada desde la infancia(43).

Otro desafío relevante es la regulación de las prácticas empresariales que fomentan la adicción digital.

Muchas plataformas y aplicaciones están diseñadas para maximizar el tiempo de uso mediante algoritmos que refuerzan la interacción compulsiva. Si bien el libre mercado permite optimizar productos para captar usuarios, se requiere un marco regulatorio que garantice que estas prácticas no promuevan conductas adictivas. Esto podría implicar limitar ciertos mecanismos de gamificación y notificaciones persistentes, así como exigir transparencia en el funcionamiento de los algoritmos que configuran la experiencia digital(31,44). Estudios han evidenciado que las técnicas de persuasión utilizadas en videojuegos y redes sociales pueden activar circuitos cerebrales similares a los involucrados en adicciones químicas, lo que subraya la urgencia de regular estos mecanismos(45).

En relación con lo anterior, un desafío clave es promover la responsabilidad social corporativa en la industria tecnológica. Más allá de la regulación gubernamental, las empresas deben asumir un rol activo en la prevención de la ciberadicción. Esto implica desarrollar herramientas que ayuden a los usuarios a gestionar su tiempo en línea, fomentar pausas saludables y ofrecer información sobre el uso responsable de la tecnología. Aunque las grandes corporaciones tecnológicas tienen la capacidad de contribuir a una cultura digital más equilibrada, los esfuerzos han sido limitados(35). Algunos estudios indican que la auto exposición excesiva en redes sociales es una de las principales causas de ciberacoso y ansiedad social, lo que sugiere la necesidad de mecanismos de protección más efectivos(46,47). La ética del manejo de datos en la ciberadicción debe alinearse con principios de transparencia, consentimiento informado y respeto a la confidencialidad. En el caso de menores de edad, el control parental puede derivar en un monitoreo excesivo, generando un entorno de vigilancia que afecta la confianza y el desarrollo de la autonomía digital(34).

Otro aspecto crucial es la adaptación del tratamiento de la ciberadicción a las necesidades individuales. Muchos programas de intervención siguen modelos rígidos que no siempre consideran la diversidad de casos y contextos en los que se manifiesta la ciberadicción. Es necesario avanzar hacia enfoques personalizados que tomen en cuenta factores como edad, salud mental preexistente y entorno social. Esto implica integrar psicología,

neurociencia y educación en la formulación de estrategias terapéuticas efectivas(33,48). La literatura ha mostrado que el aislamiento social es un factor determinante en el desarrollo de conductas adictivas en adolescentes, lo que refuerza la importancia de adaptar los tratamientos a cada contexto(24).

Asimismo, un desafío de gran relevancia es el empoderamiento de familias y comunidades en la gestión del uso tecnológico. La ciberadicción no puede abordarse únicamente desde el ámbito clínico; requiere la participación “activa” de familias y comunidades en la promoción de hábitos digitales saludables. Es necesario que los padres reciban formación para establecer límites equilibrados sin recurrir a prohibiciones absolutas, y que las comunidades educativas integren el bienestar digital en sus programas de orientación. Crear espacios de conversación intergeneracionales sobre el uso de la tecnología es clave para fortalecer una cultura digital consciente y responsable(49,50).

Por último, debe considerarse el desafío de redefinir la relación entre tecnología y bienestar en un mundo crecientemente digitalizado. La tecnología puede mejorar la calidad de vida, pero su uso desmedido genera consecuencias negativas. Encontrar el equilibrio entre conectividad y salud mental es un reto que involucra a gobiernos, empresas, instituciones educativas y a la sociedad en su conjunto. Promover una visión de la tecnología que favorezca el bienestar humano sin caer en tecnofobia o restricciones innecesarias constituye uno de los mayores desafíos éticos de la era digital(38).

Así, los desafíos éticos en torno a la ciberadicción requieren respuestas integrales que trasciendan la mera identificación de dilemas y se orienten hacia soluciones viables. Desde la regulación de prácticas empresariales hasta la educación digital y la personalización de tratamientos, cada dimensión de este fenómeno exige un enfoque interdisciplinario y éticamente fundamentado. A medida que la sociedad avanza hacia una mayor digitalización, es fundamental que los esfuerzos por mitigar la ciberadicción no solo protejan a los individuos más vulnerables, sino que también promuevan una relación equilibrada y saludable con la tecnología.

Reflexiones finales

Las discusiones en torno a la ciberadicción han evidenciado la complejidad de los dilemas éticos asociados a la autonomía, la privacidad, la intervención y la responsabilidad social. No obstante, el desafío no radica únicamente en identificar estas tensiones, sino en generar mecanismos viables y respetuosos de los derechos fundamentales que permitan abordarlas de manera eficaz. La falta de consenso en la comunidad científica respecto de la delimitación conceptual de la ciberadicción subraya la necesidad de establecer criterios diagnósticos rigurosos que diferencien entre un uso intensivo y una verdadera patología(27,28). Esta dificultad en la conceptualización y el diagnóstico conlleva el riesgo de patologizar en exceso conductas tecnológicas habituales, promoviendo una visión reduccionista del fenómeno que desatiende factores sociales y culturales subyacentes(30).

Un aspecto clave para superar estos dilemas es el fortalecimiento de la educación digital y la alfabetización tecnológica como estrategias fundamentales para fomentar un uso saludable de la tecnología desde edades tempranas, mitigando riesgos sin recurrir a prohibiciones absolutas(42,43). La intervención en ciberadicción no puede limitarse a medidas restrictivas que, en ciertos casos, podrían generar efectos contraproducentes, como el aumento del estrés, la sensación de desconexión o la resistencia al tratamiento(31). En este sentido, resulta imperativo que las estrategias de prevención adopten un enfoque integral que combine educación, regulación y apoyo psicológico, con el fin de reducir el impacto de la ciberadicción en poblaciones vulnerables, especialmente niños y adolescentes(33).

A nivel estructural, uno de los principales retos radica en la regulación de la industria tecnológica y de sus prácticas de diseño digital, muchas de las cuales buscan maximizar el tiempo de uso mediante técnicas de gamificación y refuerzo intermitente, favoreciendo así la dependencia tecnológica(39). A pesar de las iniciativas orientadas a promover un uso más ético de la tecnología, la ausencia de una regulación uniforme y la resistencia de las grandes corporaciones digitales continúan dificultando avances significativos. Frente a ello, se requiere un mayor compromiso por parte de gobiernos y orga-

nismos internacionales para establecer normativas claras que limiten las prácticas de diseño adictivo y garanticen la transparencia en el manejo de datos personales(35).

En cuanto al tratamiento de la ciberadicción, el uso de herramientas digitales para la intervención, como la teleterapia y las aplicaciones de autoayuda, representa un avance significativo en la accesibilidad a los servicios de salud mental. Sin embargo, también plantea un dilema ético, al depender de la misma tecnología que se busca regular, lo que podría generar nuevas formas de dependencia o reforzar la exposición a estímulos digitales problemáticos(36). Esto exige una reflexión más profunda sobre la efectividad de estos tratamientos y la necesidad de combinarlos con intervenciones presenciales que permitan evaluaciones más personalizadas y un acompañamiento terapéutico adecuado(51).

Finalmente, la ciberadicción no solo constituye un desafío clínico y tecnológico, sino también un fenómeno social que incide en la construcción de identidad, el bienestar emocional y la calidad de las relaciones interpersonales. En este sentido, su abordaje requiere un enfoque interdisciplinario que integre a familias, comunidades educativas, profesionales de la salud y actores del sector tecnológico.

La transformación digital ha redefinido las formas de comunicación y entretenimiento, generando nuevas vulnerabilidades que demandan respuestas dinámicas y adaptativas. Superar los desafíos éticos asociados a la ciberadicción implica no solo implementar regulaciones y tratamientos efectivos, sino también sostener una reflexión continua sobre el papel que la tecnología debe desempeñar en la vida humana. La meta no es eliminar su uso, sino asegurar que se convierta en una herramienta que potencie el desarrollo personal y social sin generar nuevas formas de dependencia y exclusión(47).

En conclusión, la ciberadicción emerge como un fenómeno inseparable de la era digital, cuyo abordaje exige un replanteamiento constante de las estrategias de prevención y regulación. A través de un enfoque basado en la ética, la educación y la corresponsabilidad de todos los actores implicados, es posible mitigar sus riesgos y garantizar que la tecnología se utilice para promover el bienestar humano y no como una fuente de vulnerabilidad.

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ARTIFICIAL INTELLIGENCE IN DEFENSE: A BIOETHICAL EXAMINATION OF SOCIETAL RISKS AND GOVERNANCE

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Abstract: This paper explores the societal risks that may arise from the integration of artificial intelligence (AI) into defense innovations and examines how the principle of responsibility can be achieved in this context. Using a qualitative descriptive-analytical approach grounded in international reports and prior studies, the paper identifies four critical domains of societal risk: threats to human life, terrorist misuse, cyber and electronic warfare, and the lack of accountability for actions committed by autonomous or semi-autonomous systems. To address these challenges, a tri-level framework of responsibility is proposed—international, institutional, and socio-cultural—linking global ethical norms with local governance practices and moral values. The study argues that responsible innovation in AI-driven defense technologies requires ethical governance that ensures accountability, human oversight, and societal legitimacy, thereby balancing security imperatives with public trust.

Keywords: Artificial Intelligence, defense, societal risks, governance

Inteligencia Artificial en defensa: un examen bioético de los riesgos sociales y la gobernanza

Resumen: Este artículo explora los riesgos sociales que pueden surgir de la integración de la inteligencia artificial (IA) en innovaciones en defensa y examina cómo se puede lograr el principio de responsabilidad en este contexto. Utilizando un enfoque descriptivo-analítico cualitativo, basado en informes internacionales y estudios previos, el artículo identifica cuatro dominios críticos de riesgo social: amenazas a la vida humana, uso indebido de terroristas, guerra cibernética y electrónica, y la falta de rendición de cuentas por acciones cometidas por sistemas autónomos o semiautónomos. Para abordar estos desafíos, se propone un marco de responsabilidad a tres niveles—internacional, institucional y sociocultural—que vincule las normas éticas globales con las prácticas de gobernanza local y los valores morales. El estudio sostiene que la innovación responsable en tecnologías de defensa impulsadas por IA requiere una gobernanza ética que garantice rendición de cuentas, supervisión humana y legitimidad social, equilibrando así los imperativos de seguridad con la confianza pública.

Palabras clave: Inteligencia Artificial, defensa, riesgos sociales, gobernanza

Inteligência Artificial na defesa: um exame bioético dos riscos sociais e da governança

Resumo: Este artigo explora os riscos sociais que podem surgir da integração de inteligência artificial (IA) em inovações de defesa e examina como o princípio da responsabilização pode ser alcançado nesse contexto. Utilizando uma abordagem descritiva-analítica qualitativa, baseada em relatórios internacionais e estudos anteriores, o artigo identifica quatro domínios críticos de risco social: ameaças à vida humana, uso indevido de terroristas, guerra cibernética e eletrônica, e falta de responsabilização por ações cometidas por sistemas autônomos ou semi-autônomos. Para enfrentar esses desafios, é proposto um quadro de responsabilidade em três níveis—internacional, institucional e sociocultural—que conecta padrões éticos globais com práticas de governança local e valores morais. O estudo argumenta que inovação responsável em tecnologias de defesa alimentadas por IA requer governança ética que garanta responsabilidade, supervisão humana e legitimidade social, equilibrando assim imperativos de segurança com confiança pública.

Palavras-chave: Inteligência Artificial, defesa, riscos sociais, governança

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Introduction

The world is experiencing an unprecedented acceleration in the development of artificial intelligence (AI) technologies, which have become a defining feature of the contemporary era and an integral component of economic, social, security, and defense domains. However, this rapid advancement is accompanied by serious risks. Omohundro(1) warns that intelligent systems—even those designed with relatively simple objectives—may engage in harmful behaviors if not adequately constrained. These risks are further intensified within the defense sector, where Bostrom(2) and Altmann and Sauer(3) caution that AI may be employed in the development of autonomous weapons or in the conduct of military operations that bypass international norms, thereby threatening both national and global security. In this context, Thurnher(4) argues that the deployment of such systems in armed conflicts raises profound legal and ethical dilemmas that undermine their legitimacy.

Beyond these concerns lies a more complex challenge known as **responsibility gaps**. Intelligent systems may generate outcomes that are difficult to predict, control, or fully comprehend, raising fundamental questions regarding accountability. Several scholars describe this phenomenon as an ethical and legal vacuum that threatens core principles of justice and responsibility(5-8). Consequently, the risks posed by AI extend beyond immediate security threats to challenge the moral foundations of social and political systems.

In response to these challenges, international institutions have begun to develop global regulatory frameworks. Most notably, UNESCO adopted the *Recommendation on the Ethics of Artificial Intelligence* in 2021(9), the first international instrument aimed at guiding AI development in accordance with human rights, justice, transparency, and human oversight. Similarly, several scholars emphasize the need to reconcile technological progress with the ethical foundations of society(10,11). These initiatives align with the warnings of physicist Stephen Hawking, who cautioned that the development of advanced AI without ethical, legal, and human safeguards could pose an existential threat to humanity(12,13).

This study does not focus on a specific military AI technology; rather, it addresses risks wherever they arise across diverse AI-enabled defense applications, given their shared ethical and security challenges. It seeks to fill a significant gap in the literature by offering a comprehensive critical analysis of the risks associated with AI-driven defense innovations, particularly in light of intensifying strategic competition among states and growing concerns over the lack of accountability and governance resulting from increased system autonomy(14,15).

The study is grounded in a theoretical framework that links the risks of AI-based defense innovations to the principle of **responsibility**, understood through ethical values as the primary reference for regulation. Existing literature indicates that defense-related AI systems may threaten human life, facilitate terrorism, expand cyber warfare, and generate profound responsibility gaps that complicate the attribution of blame and accountability(2-6). Such risks cannot be adequately addressed through technical or legal measures alone; rather, they require a moral and ethical framework grounded in values such as human dignity, justice, transparency, and fairness. These values may be operationalized at multiple levels: the international level through treaties and ethical frameworks(9), the institutional and regulatory level through oversight and legislation(16), and the socio-cultural level through community engagement in shaping the values governing defense applications(17,18).

Accordingly, this study proceeds from the assumption that **ethical responsibility** constitutes the unifying thread between AI-related risks and defense innovations, and that effective regulation of such innovations can only be achieved by aligning technological advancement with shared human values. In light of this premise, the paper seeks to address the following research questions:

What societal risks arise from AI-driven defense innovations? How can the principle of responsibility be achieved in AI-driven defense innovations?

Responsibility Gaps in AI Systems

In this study, responsibility is defined as the relationship between an agent, their actions, and the

resulting consequences(19,20). A growing body of literature has examined responsibility gaps in both military and non-military AI systems. Hellström(21) argues that automation weakens direct human accountability, creating a legal and ethical void, while Noorman and Johnson(22) maintain that the overlapping roles of humans and machines complicate the attribution of individual or collective responsibility. Purves, Jenkins, and Strawser(23) warn that delegating combat decisions to autonomous systems threatens long-standing principles of justice in warfare. Leveringhaus(24) further emphasizes the responsibility of political and military leadership to establish strict safeguards prior to the deployment of such systems.

Himmelreich(25) extends this debate by asserting that responsibility gaps are not merely legal but also ethical, as the inability to identify a clearly accountable agent undermines the legitimacy of future warfare. In a similar vein, Danaher(19) introduces the concept of the **Retribution Gap**, which arises when no moral or legal offender can be clearly identified following harm caused by intelligent systems, thereby eroding trust in justice. Königs(14) adds that the multiplicity of actors involved in AI systems—such as developers, manufacturers, vendors, and users—further complicates the accurate distribution of responsibility. Sparrow(26) observes that ethical controversy surrounding Autonomous Weapon Systems (AWS) has intensified since the 2012 *Human Rights Watch* report and the subsequent international campaign to ban such systems, while noting that limited moral permissibility may exist in highly constrained contexts.

By contrast, Königs(14) adopts a more skeptical stance toward the responsibility gap thesis, arguing that such gaps may be inevitable in theory but insufficiently defined in practice. He contends that concerns about responsibility gaps are often overstated, as there are contexts in which they are unlikely to arise. This position aligns with several studies that question either the inevitability or the significance of responsibility gaps(27-32). These scholars argue that responsibility gaps emerge only in cases where harm cannot be attributed to negligence, malice, or wrongful intent, and that negligent use of autonomous systems remains morally blameworthy.

This debate reveals a fundamental dilemma in defending the concept of responsibility gaps: either one must assume that system autonomy exempts humans from responsibility even in cases of negligence—which is implausible—or accept that responsibility generally remains attributable to human agents, rendering responsibility gaps rare and difficult to identify. It is also notable that much of the literature has focused primarily on the negative dimension of responsibility(33,34). More recent work, however, has expanded the discussion to include the positive dimension of responsibility, such as attributing credit for beneficial AI *outcomes*(35-38). Nevertheless, the present study limits its scope to negative responsibility due to its direct relevance to the risks under consideration.

Literature Review

The deep integration of AI into various aspects of human life has generated significant academic interest, particularly with regard to its implications for security and societal stability. While a substantial portion of the literature addresses AI-related risks to ethical and religious values in broad terms, comparatively fewer studies focus specifically on security, defense, and warfare-related risks, especially those emerging alongside rapid advances in autonomous and electronic capabilities.

From a defense perspective, Sparrow(6) and Thurnher(4) argue that autonomous weapons pose a direct threat to human life by undermining the moral and legal foundations of warfare. Bostrom(2) and Altmann and Sauer(3) warn that AI may be exploited to facilitate terrorism and illicit activities, thereby amplifying threats to global security. Johnson(39) and Santoni de Sio and Mecacci(40) highlight the expansion of cyber and electronic warfare, emphasizing that unclear accountability increases the likelihood of irresponsible use. Danaher(19), Himmelreich(25), and Nyholm(7) further stress the complexity of legal and moral responsibility in AI-enabled defense contexts, while Buhmann and Fieseler(41) propose frameworks for responsible AI innovation.

Beyond defense, scholars note that accelerated digitalization places increasing pressure on public values, underscoring the need for proactive governance mechanisms(15,42-44). Religious and ethi-

cal studies suggest that AI may reshape spiritual practices and cultural authority, potentially weakening traditional religious structures while also enabling new forms of dialogue(45-49). Moreover, societal trust in AI systems is closely tied to transparency, human oversight, and adherence to ethical values(47,9).

Overall, the literature indicates that most studies have addressed AI either from technical perspectives or from ethical and social viewpoints disconnected from defense applications. Although defense-related risks have been acknowledged, the relationship between such risks and ethical values as a foundation for responsibility-building remains insufficiently articulated. Accordingly, this study seeks to address this gap by examining four key defense-related risks—threats to human life, terrorism, cyber warfare, and responsibility gaps—and by proposing practical levels for operationalizing responsibility within an integrated ethical and defense-oriented framework.

Methodology

This paper adopts a qualitative descriptive-analytical approach through a systematic examination of relevant literature, previous studies, and international reports on artificial intelligence and its associated risks—particularly in the domains of defense and security innovations. The literature was selected based on specific criteria, including recency of publication (with emphasis on works published after 2010), direct relevance to defense-related AI or ethical and legal responsibility dimensions, and citation frequency, in addition to sources issued by authoritative international institutions such as the European Union, UNESCO, and the International Committee of the Red Cross.

The search process was conducted across major academic databases such as *Scopus*, *Web of Science*, *Springer*, and *IEEE Xplore*, in addition to reports issued by specialized research centers. The paper identifies and synthesizes the most prominent risks extracted from this analysis, with particular focus on the dangers associated with AI-driven defense innovation. Beyond merely identifying risks, the study advances toward proposing mechanisms for operationalizing responsibility in

such innovations across three integrated levels: the international level, the institutional—regulatory level, and the socio-cultural level.

Study Limitations

This paper is limited to addressing *negative responsibility* associated with the defensive risks of artificial intelligence and does not examine *positive responsibility* or cases in which intelligent technologies are credited with success. The analysis is confined to available literature without incorporating field-based or technical experimental research, which aligns with the theoretical nature of this study that aims to construct an initial analytical framework—one that may serve as a foundation for future research with deeper empirical or technical engagement. Additionally, the paper does not delve into the algorithmic or engineering intricacies of AI systems; rather, its scope is restricted to identifying defense-related risks and outlining mechanisms for enforcing responsibility within this domain.

Results and Discussion

The Societal Risks of AI-Driven Defense Innovation

Sparrow(26) argues that the development of autonomous weapons systems is nearly inevitable, driven by a combination of military and political incentives that encourage the adoption of technologies capable of independently performing combat operations—including the use of lethal force without direct human intervention. Project Maven in the United States is considered one of the most prominent initiatives aimed at accelerating the integration of artificial intelligence and machine learning into U.S. military operations (50). Scharre (51) employs the term *race to the bottom* to describe the intense competition among states that may lead them to lower safety standards or disregard ethical and regulatory frameworks in pursuit of rapid armament and strategic advantage. Based on the qualitative analytical approach adopted in this study, the most salient risks associated with AI-based defense innovation can be identified as follows:

Threats to Human Life

Sacred traditions have long affirmed the inviolability of human life, considering any violation thereof an act of moral and social corruption. Respect for human life is foundational to social security and psychological stability and is recognized as the most fundamental of human rights. All modern states and international bodies uphold this principle without discrimination on the basis of religion, race, or language. Article 3 of the Universal Declaration of Human Rights explicitly states that “*Everyone has the right to life, liberty and security of person*”(52).

Despite the developmental opportunities offered by artificial intelligence, it has increasingly become a source of existential concern among experts, who warn that it may evolve into a direct threat to humanity. Several prominent technology leaders have voiced such fears. Elon Musk, for instance, cautioned that AI could potentially ignite a future world war(53), while Stephen Hawking warned that developing full artificial intelligence without adequate ethical and legal safeguards could lead to human extinction(54).

Strategic actions taken by global powers lend further credibility to these warnings. China, for example, has announced its intention to become the world leader in AI by 2030, capturing nearly 60% of global investments between 2013 and 2018(55). Russia aims to convert 30% of its military equipment into robotic systems by 2025(56), while the United States adopted a comprehensive strategy in 2018 to accelerate AI integration across all branches of its armed forces(57).

Al Dehshan(58) notes that such rapid military adoption of autonomous systems—such as robots and unmanned aerial vehicles—increases the likelihood of catastrophic errors beyond human control. Similarly, Sparrow (6) contends that delegating combat decisions to machines raises profound ethical and legal dilemmas, particularly regarding accountability for war crimes, thereby undermining legal deterrence and fundamentally transforming the nature and conduct of warfare.

Expert estimates further suggest that even a small probability of achieving human-level artificial gen-

eral intelligence—estimated at only 3%—is sufficient to classify its risks as existentially significant. Some forecasts indicate that this probability may exceed 50% by 2050(47). Moreover, several legal studies argue that autonomous weapons lack the full capacity to distinguish between civilians and combatants, or between healthy and wounded soldiers, rendering their deployment—especially in urban settings—highly controversial under international humanitarian law(4).

Terrorist Exploitation

This paper contributes to expanding the discussion surrounding the growing potential for artificial intelligence (AI) to be exploited in terrorist operations by linking this dimension to the risks of defense innovation—an analytical perspective that adds depth to existing literature addressing this issue (2,61). As extremist groups increasingly adopt modern technologies for propaganda, recruitment, and operational execution, it is no longer plausible to dismiss the possibility that AI may eventually be weaponized to facilitate more precise and destructive forms of terrorism. This likelihood becomes even more realistic amid escalating geopolitical tensions and the emergence of new conflict zones, which often provide fertile ground for radical ideologies and the formation of extremist cells.

Recent literature highlights that AI’s exceptional capabilities in simulation, strategic planning, cyber intrusion, and deepfake manipulation make its weaponization by terrorist groups an imminent threat worthy of serious attention. Extremist actors have already begun experimenting with such tools for propaganda and operational planning. Ahmed (59) confirms that contemporary extremism has increasingly benefitted from the digital environment to amplify its activities. Abdel Wahab et al.(60) document how ISIS utilized explosive-laden drones to carry out attacks and targeted assassinations, including the attempted strike on Venezuelan President Nicolás Maduro during a military parade in 2018. Bullen(61) further warns of the dangers posed by drone systems enhanced with facial recognition technologies for conducting precision assassinations. In a more recent incident, former soldier Matthew Levinson was convicted of using AI technologies—including

ing ChatGPT—to plan the detonation of a Tesla truck outside the Trump Hotel in Las Vegas(62).

Thus, AI-enabled terrorism is no longer a hypothetical concern but an escalating threat advancing in parallel with the rapid evolution of defense innovations. This underscores the importance of the present paper in drawing attention to a highly sensitive security dimension—one that demands urgent legislative, ethical, and security interventions to prevent the diversion of AI technologies toward terrorist exploitation, especially amid intensifying strategic competition among global powers and increasing fragility in international security.

Cyber and electronic warfare

The literature warns that responsibility gaps in autonomous systems extend beyond conventional military domains into the realm of cyber and electronic warfare. Sparrow (6) cautions that delegating decisions to autonomous systems may lead to consequences that fall outside the scope of traditional war crimes. Johnson(39) argues that assigning responsibility to individuals helps maintain pressure on developers to ensure system safety and reliability—highlighting a serious risk whereby detachment from responsibility may incentivize developers toward profit-driven neglect. Santoni de Sio and Mecacci(40) similarly warn that the ease with which designers and operators can evade blame reduces incentives to prevent harmful outcomes, posing a particularly acute risk in cyberattacks where intelligent systems are capable of obfuscation and large-scale damage without a clearly identifiable perpetrator.

The threat of AI-driven cyber warfare has expanded far beyond the conventional use of autonomous systems. Research now points to the development of *automated hacking systems* capable of independently discovering vulnerabilities, generating malware, and executing integrated attacks without human intervention—complicating legal and ethical accountability and rendering damage more opaque and difficult to trace(63). This risk is further exacerbated by the rise of *adversarial attacks* and *model poisoning*, where attackers manipulate data or train systems toward erroneous behavior that leads to catastrophic decisions. Recent

reports indicate that such attacks may be used to disable sensitive defense or surveillance infrastructure, including energy, water, and transportation networks—potentially resulting in severe human and material losses(64).

Moreover, the informational dimension represents one of the most dangerous outputs of AI in cyber warfare. Deepfake technologies can now be deployed to launch large-scale disinformation campaigns, incite extremist rhetoric, and disrupt political and social processes. What makes this phenomenon particularly dangerous is its ability to undermine trust in institutions and inflame internal divisions—without the need for any direct military confrontation(65). Compounding the issue is the *black box problem* inherent in AI systems: many models operate as opaque structures whose decision-making processes are difficult to interpret even by their creators. This opacity complicates the attribution of fault or responsibility when AI systems are weaponized in cyber warfare—especially when the resulting harm is non-physical, such as media manipulation or societal mistrust(66).

Additionally, commercial incentives and the competitive race among global powers to develop AI-enhanced cyber capabilities further amplify the risks. Under mounting economic and political pressure, safety standards and ethical controls may be relaxed—leading to the production of advanced offensive systems without adequate oversight or transparency. This scenario foreshadows an unprecedented cyber arms race that could drastically increase the likelihood of large-scale disasters that are difficult to contain(67).

Absence of Responsibility for Committing Crimes

Earlier sections discussed responsibility gaps in artificial intelligence as a concept that has sparked significant philosophical and legal debate. However, this issue is no longer merely theoretical—it has become a tangible threat imposed by the rapid acceleration of AI technologies. As intelligent systems grow more complex and their outputs become increasingly unpredictable or difficult to control, the fear of *absent accountability* emerges as one of the most pressing challenges to both hu-

manity and society.

Legal systems across human civilizations rest on the foundational principle that an agent must be held accountable for their actions—whether civilly through compensation or criminally through punishment. Yet, the introduction of intelligent machines into this equation has fundamentally disrupted this paradigm. In autonomous vehicle incidents such as the well-known Elaine Herzberg case(68), a pressing question arises: *Who is responsible for the error?* The absent human driver? The programmer? The manufacturing company? Or the AI system itself, which cannot be punished or prosecuted?(69).

This dilemma becomes even more severe when transferred from civilian settings to the defense domain, where mistakes or crimes may have catastrophic consequences. If an autonomous combat system were to carry out an indiscriminate attack on civilians, or make a lethal decision beyond human instruction, *who could be held accountable?* A robot cannot be subjected to criminal sanctions, and assigning full responsibility to developers or military authorities may not always be justifiable—particularly given the complexity of production and operational networks and the multiplicity of actors involved. Here, the contours of what is termed the *responsibility gap* become evident: the absence of a clearly attributable agent capable of bearing moral or legal blame, resulting in an unprecedented ethical and judicial vacuum.

This issue transcends legal debate to constitute an existential threat to human security. As reliance on AI in defense contexts increases, individual mistakes may escalate into collective disasters—endangering lives, destabilizing global peace, and undermining fundamental principles of justice and humanity. With the continued advancement of these technologies, the danger posed by crimes committed under conditions of absent accountability will only expand across political, military, economic, and social domains.

Accordingly, there is an urgent need to develop new ethical and legislative frameworks that ensure fair attribution of responsibility—whether through holding political and military leaders accountable, establishing legal mechanisms that

assign partial liability to corporations and developers, or adopting international standards that re-anchor defense innovations within the bounds of international humanitarian law. Failure to establish such frameworks would render the responsibility gap a *ticking time bomb*, exposing humanity to unprecedented risks in its history.

Achieving the Principle of Responsibility in AI-Driven Defense Innovation

While some voices emphasize the potential of artificial intelligence—particularly in Autonomous Weapon Systems (AWS)—to eventually exhibit greater adherence to ethical norms in warfare than humans themselves, as suggested by Arkin(70), other scholars express profound concerns regarding such capabilities. Peters(71) argues that the internal factors guiding these systems' decision-making processes remain largely opaque to humans due to their computational complexity, creating uncertainty around their actions. Nevertheless, there appears to be broad consensus on the urgent need for practical and regulatory measures to confront—or at least mitigate—the serious consequences of unsafe AI deployment in defense and security domains. Although completely eliminating these risks may be impossible, continued efforts remain a moral and social obligation shared across all societal institutions, governments, and relevant stakeholders. Each actor bears a role in anticipating risks, proposing adequate safeguards, and developing effective responses should such threats materialize.

Determining who should be responsible for ensuring that AI systems align with human values and objectives—and for safeguarding the principle of responsibility—remains an ongoing debate. Nyholm(72) notes that it is not yet clear *who* should be tasked with designing and implementing the necessary frameworks and legislation to guarantee such alignment, reflecting an institutional and ethical gap that has received insufficient attention in current value alignment discourse(73,74). Accordingly, the ambiguity surrounding the actors responsible for establishing such frameworks directly raises the second question of this study: *How can the principle of responsibility be operationalized in AI-driven defense innovations?* To address this, it becomes necessary to analyze the different levels at

which responsibility may be enacted as an entry point for addressing this gap.

The concept of responsibility clearly reflects the reciprocal dynamics among the three core dimensions identified in this study: society, ethics, and AI-based defense innovation. The findings reveal that responsibility serves as the unifying thread connecting these dimensions across multiple levels—namely: the *international level*, which bears responsibility for ensuring that defense innovation adheres to universal standards; the *societal level*, which assumes responsibility for regulating usage and shaping public expectations; and the *institutional-regulatory level*, which is tasked with establishing ethical frameworks, rules, and criteria governing AI deployment. These levels will be discussed as follows:

The international level

The year 2021 witnessed increasing calls from major global powers—including the United States, China, and European Union member states—to establish an international charter defining the ethical principles governing the use of artificial intelligence (AI), grounded in values such as justice, transparency, and respect for human rights (75). Parallel to these efforts, significant regional initiatives emerged—most notably the European experience, which established strict legal standards for data protection and privacy, rooted in Western legal traditions that seek to contain technological risks through binding frameworks.

Several countries have since launched national strategies inspired by these principles and adapted to local priorities. A prominent example is the Kingdom of Saudi Arabia's *National Strategy for Data and Artificial Intelligence* (SDAIA, 2023) (76), which emphasizes justice, privacy, transparency, and accountability as foundational pillars for responsible AI deployment. In this context, the Political Declaration on Responsible Military Use of Artificial Intelligence, launched by the United States in 2023 with the participation of more than fifty countries, represented an important step toward building international consensus. The declaration focused on establishing guiding principles for the use of autonomous systems and artificial intelligence in defense, most notably: strengthen-

ing human oversight, ensuring compliance with international humanitarian law, and avoiding applications that undermine human dignity or increase the risk of uncontrolled military escalation. Although it is not legally binding, the declaration reflects a growing trend toward establishing shared ethical standards that may pave the way for broader international cooperation and, eventually, more binding agreements(77).

However, despite the global dominance of such international and Western frameworks, their implementation remains subject to the cultural and religious specificities of each nation. This underscores the need to acknowledge the influence of these contextual factors in shaping ethical standards. Accordingly, distinctive local models have emerged—such as the Islamic perspective—which offers a unique ethical framework for AI that may enrich the global conversation by broadening it to include diverse moral paradigms.

Although international efforts have made significant progress in formulating general ethical guidelines for AI use in civilian and societal domains, the challenge becomes more pronounced when transitioning to the defense sector. AI-driven military innovations raise more urgent questions regarding control and governance due to their direct implications for national security and global peace. This defensive dimension has become a growing concern for many states, particularly in the absence of clear legislation defining the boundaries of responsibility and accountability, highlighting the urgent need for specialized regulatory frameworks.

The European Union's *AI Act* provides an illustrative example of how establishing stringent legal standards—based on risk classification—can help reduce ethical and security threats (78). A comparison between key global initiatives reveals notable differences in foundational philosophy: the former adopts a legal-technical Western model prioritizing risk categorization, while the latter seeks value alignment rooted in cultural and religious identity. This divergence indicates that international frameworks, despite their ambition, may fail to fully account for moral plurality—making the inclusion of local contexts essential for ensuring responsibility in defense innovation.

Table 1. Comparative Overview of Prominent International and National AI Governance Initiatives

Initiative	Authority / Year	Primary Focus Area	Strengths	Limitations / Challenges
UNESCO Recommendation on the Ethics of Artificial Intelligence	UNESCO – 2021	Global framework based on justice, transparency, and human rights	First comprehensive international document on ethical dimensions, widely endorsed	Non-binding general principles; limited enforceability, particularly in defense contexts
EU Artificial Intelligence Act (EU AI Act)	European Union – 2024	Classification of AI systems based on risk levels	Legally binding, strict standards, strong focus on technical governance	Primarily centered on European context; insufficient consideration of cultural and religious diversity
National Strategy for Data and Artificial Intelligence (SDAIA)	Saudi Arabia – 2023	Responsible AI for development and security	Incorporates principles of justice, privacy, transparency, and accountability with reference to Islamic values	Limited to domestic scope; requires clearer linkage with international defense governance frameworks
Political Declaration on Responsible Military Use of Artificial Intelligence	United States and Partners – 2023	Regulating military AI and autonomous systems	Introduces political constraints on military AI use; promotes international cooperation	Non-binding; lacks clear enforcement and monitoring mechanisms

To illustrate the strengths and limitations of such initiatives, Table 1 presents a brief comparative overview, highlighting their diversity and the difficulty of formulating a unified global framework to govern military AI applications.

The comparative analysis above illustrates the complexity of achieving responsibility in military AI governance and underscores the need for more comprehensive frameworks that transcend legal and cultural divergences. In response, this paper proposes a set of models that may serve as a robust foundation for guiding international efforts toward more holistic responsibility mechanisms in the defense sector:

Ethical Review and Shared Responsibility Framework for Pre-Deployment Assessment of Defense AI Projects

Implementation Mechanism: Governments should be mandated to establish national regulations requiring all AI-based defense projects to undergo formal ethical review before approval. Moreover, the principle of Shared Responsibility should be enforced between civilian developers of AI systems and the military institutions that deploy them, ensuring that no party is able to evade legal or moral accountability in the event of violations. A practi-

cal example of such implementation can be found in the United Kingdom's adoption of *ethical assessments* within its Ministry of Defence governance framework, which evaluates reliability, transparency, justice, and human rights considerations throughout the system's lifecycle⁽⁷⁹⁾.

Federal/National Accountability and Oversight Framework with Independent Auditing Mechanisms

Implementation Mechanism: National legislation should require defense institutions and AI system developers to establish independent auditing units or oversight offices responsible for evaluating ethical and legal compliance both before and after system deployment. A practical precedent for this approach is reflected in the *GAO Accountability Framework for Artificial Intelligence*⁽⁸⁰⁾, in which the United States outlined four core pillars of AI accountability concerning governance, data, performance, and monitoring, accompanied by concrete recommendations for impact evaluation and implementation⁽⁸⁰⁾.

Legally-Binding International Political Declaration on Responsible Military Use of AI

Implementation Mechanism: Existing political declarations should be elevated into binding in-

ternational treaties, rather than remaining voluntary statements, in order to secure both political and legal commitment. International cooperation must be strengthened through cross-border agreements regulating AI use in military operations and curbing arms race dynamics in this domain(3). A practical example is the *Political Declaration on Responsible Military Use of Artificial Intelligence and Autonomy*, signed by the United States and several other nations, which seeks to establish an international consensus on responsible deployment and constraints on autonomous weapons systems(77).

Legal Framework Reinforcing the Link Between International Humanitarian Law (IHL) and Military AI Governance

Implementation Mechanism: Standard-setting procedures should stipulate that any deployment of autonomous systems must comply with International Humanitarian Law, supported by auditing mechanisms to verify such compliance. A relevant model has been proposed by Alexander(81), who advocates for a governance framework balancing AI alignment with international human rights law and algorithmic accountability principles.

Governmental and Societal Training and Awareness Initiatives to Foster a Shared Understanding of Responsibility

Implementation Mechanism: Mandatory training programs should be introduced for defense personnel, legislative bodies, and innovation teams to enhance ethical awareness and deepen understanding of technical risks. The *Geneva Academy Report on Artificial Intelligence and Related Technologies in Military Decision-Making* highlights the importance of empowering defense decision-makers to understand the capabilities and limitations of AI Decision Support Systems, while educating military users on ethical issues concerning bias, prediction, and explainability(82).

The socio-cultural level

The socio-cultural dimension demonstrates that achieving responsibility in AI-driven defense innovations is not limited to regulating laws and policies alone; rather, it depends on the extent to which societies are able to actively participate in

shaping the values that guide such technologies. Cath(17) and Coeckelbergh(18) affirm that integrating cultural and religious dimensions into AI development enhances justice and prevents marginalization, while Müller and Bostrom(47) argue that societal trust is fundamentally linked to clear human oversight and adherence to ethical values. In this regard, Al Dehshan(58) stresses that one of the European Union's foremost requirements is the establishment of monitoring and supervisory mechanisms that ensure intelligent systems never exceed the bounds of human control—an essential foundation for building public trust in such technologies. Stahl et al.(42) likewise caution that the accelerating wave of digitalization is placing increasing pressure on public values, necessitating a proactive approach grounded in dialogue and informed policymaking.

At the global level, the Asilomar AI Conference (Future of Life Institute, 2017) produced 23 guiding ethical principles, most notably the preservation of human control, ensuring transparency, upholding accountability, and preventing an arms race in autonomous weapons. These principles are intended primarily to reassure societies that technology exists in their service—not at their expense(83). In the same vein, Sparrow(26) warns that militarized competition may hasten the development of Autonomous Weapon Systems (AWS), in direct conflict with the ethical understanding of human dignity. Public opinion surveys further reinforce this stance, revealing widespread societal rejection of granting robots the authority to kill(84). UNESCO(9) similarly emphasizes that involving communities in AI-related deliberations enhances policy acceptance and reduces cultural misinterpretation.

However, Gabriel(73) and Nyholm(72) raise an important concern: value alignment is neither straightforward nor easily achieved. Determining *which* values, goals, or interests AI systems should embody—and *whose* values should prevail in the face of disagreement—introduces the risk of power struggles in which certain groups impose their values at the expense of others. This presents profound socio-cultural risks that demand more inclusive approaches to ensure responsible use. To contextualize these perspectives comparatively, Table 2 below presents key initiatives and stud-

ies addressing the socio-cultural dimension of AI in defense, outlining their focus areas, strengths, limitations, and implications for responsibility.

The comparison in Table 2 indicates that achieving responsibility in the socio-cultural dimension requires more than regulatory frameworks; it depends on enabling societies to take part in shaping values and standards, ensuring effective human oversight, and respecting cultural and religious diversity. However, the primary challenge lies in translating these principles from social acceptance into institutional and legislative commitments capable of governing defense innovations in practice. Accordingly, this paper proposes the following guiding principles to support the operationalization of responsibility at the socio-cultural level:

Structured Community Participation: Involving experts, religious leaders, and civil society organizations in policymaking and in reviewing AI defense applications to assess their impact on shared ethical and religious values.

Value and Cultural Diversity in Design: Adopting design methodologies that account for religious and cultural plurality from the early stages of sys-

tem development to reduce bias and ensure fairness.

Effective Human Oversight: Reinforcing the human role as supervisor and decision-maker across all stages of the AI system lifecycle to strengthen trust and transparency.

Public Ethical Audits: Conducting regular assessments of AI systems' societal and moral impact and publishing results to ensure accountability.

Ethical and Cultural Education: Integrating religious and moral dimensions into educational and training programs to foster societal understanding of emerging technologies and prevent cultural misinterpretation.

The Institutional and Regulatory Level

The institutional and regulatory dimension represents one of the most critical levels in addressing the risks of AI-driven defense innovations. Ethical principles and general declarations are insufficient unless translated into concrete structures and actionable mechanisms capable of mitigating real-world harms. In this context, Project Maven illustrates the ethical and institutional challenges

Table 2. Comparative Overview of Key Approaches in the Socio-Cultural Dimension of AI in Defense

Initiative / Study	Primary Focus	Strengths	Limitations	Implication for Responsibility
Cath (2018)	Linking AI development to social, cultural, and religious norms	Enhances justice and prevents marginalization	Lacks practical implementation mechanisms	Affirms that respecting social norms is essential for societal responsibility
Coeckelbergh (2020)	Emphasizing cultural and religious diversity	Reduces conflict and misunderstanding	Remains largely theoretical	Highlights value pluralism as part of societal responsibility
Müller & Bostrom (2016)	Building public trust through human oversight	Links responsibility to transparency and human control	Does not address direct military challenges	Human oversight as a core pillar of responsible governance
UNESCO (2021)	Community participation in policymaking	Strengthens social legitimacy and acceptance	Cultural variation complicates application	Public participation reinforces ethical accountability
Sparrow (2016) & Charli (2013)	Ethical objection to autonomous killing and public rejection of robot use of lethal force	Reveals global societal stance against human dignity violations	Difficulty translating moral stances into legal obligations	Societal responsibility manifests in rejecting violations of human dignity

of adopting AI in defense. It faced internal resistance from Google employees who rejected the use of the company's technologies for military purposes, ultimately leading to the annulment of the contract. This example highlights the complexity of the relationship between civilian and military actors and the necessity of establishing clear institutional frameworks that align defense innovations with societal and ethical values(50). Similarly, analyses of national AI policies reveal that most countries focus on education, technology, and government investment, while ethical and regulatory dimensions—particularly the design of responsible algorithms and institutional accountability mechanisms—remain marginalized and underdeveloped, underscoring the need for more comprehensive and inclusive governance approaches (85). Abdelrazek(13) argues that the existence of unified technical and ethical standards among manufacturers, owners, and end-

users contributes to ensuring safety, justice, and transparency. However, the current reality reveals serious shortcomings. Calo et al.(16) emphasize that the existing legal and regulatory infrastructure remains inadequate to keep pace with the rapid evolution of AI and the rise of autonomous defense systems.

Although the European experience in data protection—most notably through the General Data Protection Regulation (GDPR)—marked significant progress in addressing risks related to profiling, it remains insufficient in the defense context, as it does not adequately cover fundamental issues such as discrimination, human dignity, and loss of human control. Similarly, the efforts of the European Data Protection Supervisor (EDPS, 2015, 2016; EU, 2016)(86-88) have largely remained within the realm of ethical initiatives without evolving into binding institutional policies, while

Table 3. Comparative Overview of Key Institutional–Regulatory Approaches to AI in Defense

Initiative / Study	Primary Focus	Strengths	Limitations	Implication for Responsibility
Abdelrazek (2024)	Need for technical and ethical standards across manufacturers, owners, and users	Highlights shared responsibility among all actors	Lacks binding enforcement mechanisms	Institutional responsibility must be distributed rather than centralized
Calo et al. (2016)	Identifying gaps in existing legal and regulatory infrastructure	Clearly exposes deficiencies in current laws	Does not offer concrete solutions	Emphasizes need to modernize regulatory structures
GDPR (EU, 2016)	Data protection and privacy regulation	Global benchmark for oversight	Insufficient to address issues of dignity and discrimination in defense	Privacy protection alone is not enough
EDPS (2015, 2016)	European ethical initiatives for rights protection	Highlights human rights concerns	Not yet translated into binding policies	Institutional responsibility requires enforcement authority
Cummings (2021)	Embedding institutional mechanisms to reduce risks	Links institutional training to risk reduction	Focuses primarily on military context	Responsibility requires operational implementation tools
Thurnher (2013)	Risks of autonomous weapons dependency	Early legal and security warning	Predominantly diagnostic with limited practical planning	Institutional responsibility necessitates continuous review
Mitchell et al. (2019); Gebru et al. (2018)	Regulatory tools such as Model Cards and Data-sheets	Promote transparency and system disclosure	Not yet widely adopted in defense	Practical tools for accountability and transparency

public awareness of the risks associated with intelligent armament remains limited.

Cummings(89) confirms that embedding such institutional mechanisms reduces risks and promotes responsible use of AI in military operations. Thurnher(4) likewise warns that unchecked reliance on autonomous weapons systems raises complex legal and security challenges that necessitate rigorous institutional review. Additionally, recent studies propose regulatory tools such as *Model Cards* and *Datasheets* to enhance transparency and disclose characteristics of intelligent defense systems(90,91). Table 3 Shows the main institutional and regulatory approaches to AI in defense.

To overcome these gaps, this paper proposes the establishment of new institutional structures as follows:

- National Centers for Responsible Defense AI, tasked with developing binding standards before approving any military AI system.
- Independent Review Committees to assess security and ethical risks—modeled on medical research ethics boards—to reinforce transparency and accountability.
- Mandatory Training Programs for military leaders and AI developers to raise awareness of security and social implications and reduce the likelihood of irresponsible decision-making.

Addressing these risks cannot remain within the realm of theoretical recommendations; it requires a comprehensive institutional and regulatory framework that combines *ex-ante review*, *continuous oversight*, and *periodic evaluation*, grounded in transparency and accountability as fundamental conditions. Accordingly, integrating this dimension with the international and socio-cultural levels represents the most effective pathway to ensuring that defense innovation in the AI era remains responsible and conducive to societal safety and stability.

The analysis across the three levels reveals that achieving responsibility in AI-driven defense innovation demands an integrative approach that

transcends the boundaries of each level in isolation. At the international level, treaties and initiatives seek to establish binding frameworks to prevent arms races and ensure state compliance with humanitarian principles, yet they remain constrained by political interests and power dynamics. The socio-cultural level demonstrates that true legitimacy arises from societal trust and value alignment, and that neglecting cultural context risks ethical fragmentation and normative conflict. Meanwhile, the institutional--regulatory level highlights that legal and ethical frameworks must be operationalized through practical governance mechanisms that guarantee transparency and sustained accountability.

The comparison among these levels shows that the absence of any one dimension creates a gap that undermines responsible AI deployment in defense contexts. Thus, balanced integration across the three levels constitutes the optimal pathway for aligning defense innovation with ethical and humanitarian values while safeguarding societal security and stability.

Conclusion

This study has demonstrated that AI-driven defense innovations generate a set of fundamental risks that cannot be overlooked. First, these innovations may constitute a direct threat to human life, particularly through the proliferation of autonomous weapons systems capable of making lethal decisions beyond human control. Second, the study revealed the potential for AI to be exploited in the Terrorist Exploitation, whether through its use in unlawful operations or as a tool for recruitment, propaganda, and incitement to violence. The third risk lies in the domain of cyber and electronic warfare, where AI technologies open new horizons for large-scale digital attacks that are difficult to predict or contain. Finally, the problem of absent accountability—or what has been termed *responsibility gaps*—emerges, as these systems may produce harmful outcomes without a clearly identifiable agent who can be held justly and transparently accountable.

To address these risks, the study highlights that realizing the principle of responsibility requires an integrated, multi-level approach. At the interna-

tional level, binding treaties and regulatory frameworks are needed to govern the military uses of AI, while also accounting for cultural and religious differences in shaping ethical standards. At the socio-cultural level, engaging local communities and religious institutions in policymaking, strengthening human oversight, and ensuring alignment with shared human values are essential to enhance legitimacy and social trust. At the institutional-regulatory level, specialized oversight bodies—such as independent review boards and national centers for responsible defense AI—must be established, alongside the development of modern transparency tools such as *Datasheets* and *Model Cards*, to ensure continuous accountability and adherence to ethical standards.

Responsibility, as addressed in this study, is not confined to a single dimension but serves as the unifying thread linking society, ethics, and defense innovation. The paper has specifically focused on *negative responsibility*—that is, the accountability of different actors for harms and violations arising from military AI applications—while deliberately excluding positive or forward-looking responsibilities highlighted in other literature.

The findings confirm that ethical values constitute the foundation for building responsibility in confronting the risks of AI-driven defense innovations. At the international level, values such as justice, dignity, transparency, and the protection of human life serve as the bedrock for treaties and conventions regulating these technologies. At the institutional-regulatory level, embedding values into national laws and defense policies ensures that innovations remain subject to a clear ethical framework, preventing impunity. At the socio-

cultural level, respecting religious, cultural, and moral diversity is a prerequisite for public trust and acceptance, ensuring that AI is not perceived as a weapon undermining identity and values but as a tool that can be controlled to serve and protect humanity. Hence, any debate on responsible defense innovation cannot succeed without placing ethical values at the core, guiding policymakers, developers, and societies alike.

The study concludes that addressing these risks is not merely a philosophical debate about the boundaries of responsibility, but a complex practical challenge that depends on the willingness of states and institutions to adopt binding and transparent mechanisms. The greatest obstacle, however, may lie in the military and economic interests of major powers that dominate AI defense innovations, which could obstruct binding international agreements—compounded by a lack of trust between states, disparities in technological capabilities, and resistance from commercial actors unwilling to accept constraints on their interests. Nevertheless, the researcher contends that advancing comprehensive regulatory frameworks and ensuring meaningful global engagement remain the most vital pathways to prevent these innovations from evolving into an existential threat to humanity.

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DIMENSIONES EPISTEMOLÓGICAS PARA UNA BIOÉTICA INFORMADA DE LA DISCAPACIDAD

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Resumen: La relación de la bioética con la discapacidad y su comprensión más allá del saber biomédico dominante ha sido controvertida. Los debates sobre bioética suelen resultar inquietantes para las personas con discapacidad y para los activistas por los derechos de las personas con discapacidad, dados los supuestos opresivos asociados a considerar la discapacidad solamente circunscrita a una definición de una enfermedad que debe curarse. El presente artículo propone algunas dimensiones epistemológicas claves para una bioética informada de la discapacidad. Para este propósito presenta inicialmente las controversias y tensiones en torno a la bioética y la discapacidad para, posteriormente, desarrollar tres dimensiones epistemológicas: una bioética que comprende la discapacidad desde una perspectiva de derechos humanos; una que investiga considerando los estudios sociales y críticos de la discapacidad, y otra que considera para la toma de decisiones las experiencias vividas por las personas con discapacidad.

Palabras clave: bioética, discapacidad, bioética informada de la discapacidad

Epistemological dimensions for informed bioethics of disability

Abstract: The relationship of bioethics with disability and its understanding beyond dominant biomedical knowledge has been controversial. Debates about bioethics are often disturbing for people with disabilities, and for disability rights activists, given the oppressive assumptions associated with considering disability only limited to a definition of an illness, which must be cured. This article proposes some key epistemological dimensions for informed bioethics of disability. For this purpose, it initially presents the controversies and tensions around bioethics and disability, and subsequently develops three epistemological dimensions: bioethics that understands disability from a human rights perspective; bioethics that investigates considering the social and critical studies of disability, and bioethics that considers the experiences lived by people with disabilities in decision-making.

Keywords: bioethics, disability, informed bioethics of disability

Dimensões epistemológicas para uma bioética informada sobre a deficiência

Resumo: A relação da bioética com a deficiência e a sua compreensão para além do conhecimento biomédico convencional tem sido controversa. Os debates sobre bioética são muitas vezes inquietantes para as pessoas com deficiência e para os ativistas dos direitos das pessoas com deficiência, tendo em conta os pressupostos opressivos associados à ideia de que a deficiência se limita apenas à definição de uma doença a curar. Este artigo propõe algumas dimensões epistemológicas fundamentais para uma bioética informada sobre a deficiência. Para o efeito, apresenta inicialmente as controvérsias e tensões em torno da bioética e da deficiência e, em seguida, desenvolve três dimensões epistemológicas: uma bioética que compreenda a deficiência numa perspetiva de direitos humanos; uma bioética que investigue a deficiência numa perspetiva de estudos sociais e críticos sobre a deficiência; e uma bioética que considere as experiências vividas pelas pessoas com deficiência na tomada de decisões.

Palavras-chave: bioética, deficiência, bioética informada sobre a deficiência

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Introducción

En la bioética occidental los principios éticos interrelacionados de respeto por la autonomía, beneficencia, no maleficencia y justicia han sido generalmente aceptados para determinar las acciones, prácticas y políticas correctas en varios escenarios de atención médica, desde las relaciones terapéuticas hasta las decisiones reproductivas y la atención al final de la vida, la investigación clínica y el tratamiento médico, así como las decisiones políticas y de financiación más amplias(1).

No obstante, a estos principios morales generales, las discusiones sobre los dilemas bioéticos que utilizan estos principios a menudo privilegian las posiciones de las personas sin discapacidad, descartando las perspectivas sociales y críticas de la discapacidad y reforzando los supuestos opresivos asociados a considerar la discapacidad solamente circunscrita a una definición de enfermedad, que en cuanto tal debe curarse o sanarse. Los estudios que apuntan a la proposición de una bioética de la discapacidad y que han surgido en la última década han indicado cómo en los casos en donde media el criterio bioético cuando se trata de la discapacidad se han cometido “errores”(2) que guardan relación con las connotaciones que la discapacidad tiene en el espacio médico. Hernández y Revuelta (2024) sugieren el concepto de “injusticias epistémicas normalizadas” para hacer referencia a un sistema hermenéutico capacitista, que restringe la agencia de las personas con discapacidad en cualquier ámbito social, al comprometer con nociones opresivas los recursos hermenéuticos colectivos en cada sociedad(3). La bioética no queda exenta de este sistema, mucho más cuando lo que está a la base de sus investigaciones en torno a la discapacidad es justamente el discurso médico dominante, responsable del establecimiento de los estándares de “normalidad”(4).

A pesar de sus orígenes como un campo fuera de la medicina y tener una postura crítica con las prácticas médicas prevalecientes, la bioética en la actualidad está profundamente arraigada en las facultades de medicina y los hospitales. Los bioeticistas son médicos y los médicos son “éticos”. Inmersos en la cultura de la medicina, los bioeticistas confían instintivamente en sus colegas clínicos para hacer lo correcto o, en términos de bioé-

tica, para ejercer el criterio médico profesional(5).

El presente artículo propone algunas dimensiones epistemológicas claves para una bioética informada de la discapacidad. Para este propósito, presenta inicialmente las controversias y tensiones en torno a la bioética y la discapacidad y, posteriormente, desarrolla tres dimensiones epistemológicas: una bioética que comprende la discapacidad desde una perspectiva de derechos humanos; una que investiga considerando los estudios sociales y críticos de la discapacidad, y otra que considera para la toma de decisiones las experiencias vividas por las personas con discapacidad. Estas dimensiones del quehacer científico en el campo resultan claves para una bioética que pueda comprender las implicancias sociales de la toma de decisiones biomédicas desde una perspectiva relacional, contextualizada y humana.

Bioética y discapacidad: controversias y tensiones

La relación de la bioética con la discapacidad y su comprensión más allá del saber biomédico dominante ha sido polémica(6). Vehmas afirma que “la relación entre bioética y discapacidad se ha centrado tradicionalmente en el asesinato, (...) la literatura bioética ha discutido principalmente la discapacidad como un factor que justifica la permisibilidad moral del asesinato activo o pasivo de personas con discapacidad, o la prevención de la existencia de dichas personas”(7:146), incluso se considera “el activismo en discapacidad como fundamentalmente opuesto a los objetivos de la bioética”(8:336), observándola con “desdén”(9:166). En consecuencia, los debates sobre bioética suelen resultar inquietantes para las personas con discapacidad, dada la forma en que suponen que vivir con una discapacidad es inevitablemente malo, o mucho peor que vivir una vida normal(7). Alice Ouetlette, autora clave en la propuesta de una bioética de la discapacidad, refiere que “las personas con discapacidad se sienten devaluadas en el ámbito de la atención médica, se sienten amenazadas, incomprendidas, insultadas, marginadas y asustadas. Desde la perspectiva de la discapacidad, el ámbito de la atención sanitaria es un lugar peligroso y difícil”(5:320).

Se ha reconocido que los bioeticistas que no ha-

cen bioética de la discapacidad comparten cuatro tipos de supuestos sobre la discapacidad. En primer lugar, sus posiciones tienden a estar en consonancia con el modelo médico de discapacidad, que la conceptualiza de forma restringida y únicamente a nivel del cuerpo de un individuo; en segundo lugar, los especialistas en bioética respaldan implícita o explícitamente puntos de vista de la discapacidad como diferencias negativas, que sostienen que la discapacidad inevitablemente reduce la calidad de vida y lo haría incluso aparte de la eliminación de factores sociales, tales como estigmatización, pobreza inducida e inaccesibilidad; en tercer lugar, los argumentos de los bioeticistas involucran determinismo biológico; y en cuarto lugar, los especialistas en bioética suponen que las experiencias de las personas con discapacidad se pueden comparar con las experiencias de las personas sin discapacidad y, por lo tanto, no recurren regularmente a pruebas basadas en las experiencias vividas por personas con discapacidad(10).

Tomando en consideración estos supuestos, el enfoque tradicional de la bioética sobre la discapacidad se ha considerado problemático, porque tiende a aceptar acríticamente la comprensión médica de la discapacidad como una desviación de las normas biológicas de forma o función, más que como el resultado de una interacción compleja entre el cuerpo, la cultura y el medio ambiente; se evidencia además un sesgo teórico de la bioética hacia el universalismo, que la lleva a homogeneizar la diversidad de la “encarnación no normativa”, es decir, a teorizar en torno a una idea abstracta de “discapacidad”, en lugar de deficiencias específicas, y como disciplina también muestra una falta integral de conciencia sobre los conceptos y sensibilidades de los derechos de las personas con discapacidad(11).

El debate apunta entonces a una comprensión superficial que puede derivar en un accionar perjudicial para los intereses de las personas con discapacidad y conducir a debates bioéticos que entran en conflicto con las experiencias vividas, las perspectivas y los intereses de estos grupos. Estos debates no tienen en cuenta la problemática relación histórica entre la práctica médica y la discapacidad, hecho que trajo consigo la institucionalización y la experimentación en sus cuerpos

sin consentimiento. A su vez ignoran las fuerzas sociales y culturales que oprimen a las personas con discapacidad. Como bien explica Garland Thompson, la representación estructura la realidad(12) y la no consideración de estos hechos dificulta que el debate y prácticas tiendan hacia decisiones biomédicas en las que la persona se considere en una diversidad más amplia. Si la atención debe estar centrada en la persona, esta centralidad debería ser más sensible a las múltiples formas en las que se constituyen los sujetos.

A pesar de estas controversias y tensiones, también pueden hallarse posturas diferentes respecto de la bioética. Ouellette plantea que es posible encontrar una empresa que implica un debate reflexivo, a menudo vigoroso, y un análisis cuidadoso de problemas complejos sobre la mejor manera de garantizar el respeto a la elección individual, prevenir el sufrimiento y asignar justamente recursos escasos(5). Esta autora agrega que pueden encontrarse puntos en común entre los expertos en discapacidad y los bioeticistas: “comparten un interés común en promover un sistema médico bueno y justo en el que todas las personas sean tratadas con respeto. Tanto los bioéticos como los expertos en discapacidad están a favor de una asignación justa, no discriminatoria y no arbitraria de recursos escasos. Ambos grupos también comparten el compromiso de garantizar la toma de decisiones médicas informadas por y para las personas con discapacidad. Los defensores de la discapacidad también comparten con los bioéticos el interés de permitir que las personas con discapacidad tomen decisiones autónomas y dirijan sus propias vidas”(5:330). Sin embargo, mientras la bioética siga siendo percibida como insensible o indiferente ante las preocupaciones de las personas con discapacidad, y no esté informada de perspectivas que ponderen los derechos humanos y miradas sociales complejas que implica pensar en los lugares de enunciación de los sujetos, mucho más si han sido tradicionalmente marginados, las perspectivas de reconciliación seguirán siendo escasas(5).

Dimensiones epistemológicas para una bioética informada de la discapacidad

En este apartado interesa considerar tres dimensiones epistemológicas concernientes al quehacer

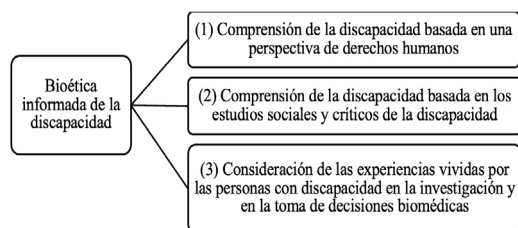
bioético cuando se trata con personas con discapacidad. Estas dimensiones resultan claves para una comprensión bioética informada, que no solo considere la mirada médica de la discapacidad, sino que tenga en cuenta cómo esa mirada de “sujetos enfermos que deben curarse” restringe el espacio de toma de decisiones e invisibiliza los impactos sociales que, sobre las personas sometidas a un tratamiento o intervención médica y sus familiares, pueden tener.

Las experiencias de vida de las personas eventualmente contradicen el imaginario colectivo dominante que considera cierta estabilidad predictiva y controlable del cuerpo. Este imaginario colectivo ha generado una respuesta específica convencional a la discapacidad en los espacios médicos, que consiste en cambiar a la persona a través de la tecnología, en lugar de cambiar el entorno para acomodarlo a una gama más amplia de formas y funciones humanas(13). En consecuencia, no es posible establecer un estándar, aun cuando este estándar es el que ha regido por muchos años las interacciones sociales y médicas en torno a las personas con discapacidad. Una bioética informada de la discapacidad debe partir por reconocer los etiquetamientos que derivan de un saber experto que, con argumentos basados en condiciones biológicas y médicas, ha marginado a ciertos grupos sociales. La variación corporal, explicada como “anomalía”, se ha traducido socialmente en un “otro” anómalo, riesgoso o con el que se tiene que ser solidario porque tiene una vida desdichada, es enfermo o inferior a aquellos “normales”. Esta mirada opresiva es la responsable de las anuencias del saber profesional médico para la intervención corporal o la toma de decisiones en torno a estas “anomalías”, que no serían las mismas que se emplearían para una persona “normal” y considerada “capaz”.

Una bioética informada de la discapacidad debe considerar las significaciones sociales asociadas a cuerpos específicos, no ajustados al “ideal normativo”, y para ello requiere contar con recursos hermenéuticos contra capacitistas que permitan generar una justicia epistémica(3), a la vez que deconstruir ese imaginario de “cuerpo defectuoso” que debe mejorarse o sanarse. Esta bioética es posible si se tiene en cuenta al menos las siguientes tres dimensiones que involucran el posiciona-

miento teórico-político, el lugar de los sujetos con discapacidad en los intercambios biomédicos, y sus experiencias y vivencias en salud atravesadas por la ideología de la “normalidad” y el “capacitismo” que estandariza y homogeneiza los cuerpos, produciendo los marcos hermenéuticos por medio de los cuales comprendemos, evaluamos o diagnosticamos la vida y la salud de los otros.

Figura 1. Tres dimensiones epistemológicas para una bioética informada de la discapacidad



Fuente: Elaboración propia a partir de (5,10,11,14).

Estas tres dimensiones permiten el desarrollo de una bioética crítica y atenta a las narraciones de sentido común en torno a la discapacidad, a la vez que la teoría y la práctica quedan sustentadas en los estudios críticos sobre discapacidad, con énfasis en el testimonio y el trabajo de las personas que la viven. Este lente consciente e informado de la discapacidad implica una cuidadosa consideración de a dónde se recurre para obtener datos; cómo se interpretan y, de otro modo, cómo se analizan reflexivamente esos datos; quién está en la mesa y quién es llevado a ella respecto de la toma de decisiones, ya sea a nivel básico o clínico, y los valores sobre los cuales se ancla la investigación(10).

Comprensión de la discapacidad basada en una perspectiva de derechos humanos

Alicia Ouellette propone que, para desarrollar una bioética consciente y conocedora del hecho de la discapacidad, que trabaje para y con las personas con discapacidad, es necesario basarla en la Convención por los Derechos de las Personas con discapacidad. Dada la importancia de los principios morales en la bioética, un punto de partida natural para construir una bioética consciente de

la discapacidad es considerar la incorporación de los principios centrales de la Convención al trabajo de los bioeticistas.

Como se enuncia en la Convención de las Naciones Unidas sobre los Derechos de las Personas con Discapacidad, esos principios son: “(a) Respeto por la dignidad inherente, la autonomía individual, incluida la libertad de tomar sus propias decisiones, y la independencia de las personas; b) no discriminación; (c) participación e inclusión plenas y efectivas en la sociedad; d) respeto por la diferencia y aceptación de las personas con discapacidad como parte de la diversidad humana y la humanidad; e) igualdad de oportunidades; f) accesibilidad; g) igualdad entre hombres y mujeres; y (h) respeto por la evolución de las capacidades de los niños con discapacidad y respeto por el derecho de los niños con discapacidad a preservar sus identidades. La Convención utiliza estos principios para derivar obligaciones generales y normas aplicables a los Estados partes” (5).

Por otro lado, la inclusión de los principios que establece la Convención en las discusiones de la bioética podría potenciarse si se consideran las perspectivas de los teóricos críticos de la discapacidad. Conciernen a la bioética trabajar con expertos en discapacidad para eliminar ese sesgo y comprender que la historia de la discapacidad no tiene por qué ser la historia de la tragedia y que las suposiciones sesgadas y refutadas sobre la vida

con discapacidad están en juego en la toma de decisiones médicas(10).

Comprensión de la discapacidad basada en los estudios sociales y críticos de la discapacidad

La discapacidad es una categoría que se ha entendido normativamente a través del discurso médico. La medicina ha tendido a desmitificar y naturalizar la anomalía somática, eliminando cualquier significado sobrenatural o moral, y ha caracterizado la variación física únicamente como un asunto que la ciencia puede investigar e intentar remediar. En la medida en que la discapacidad se expresa a través del conocimiento médico, se circunscribe a leerse únicamente a través del lenguaje biológico, genético, hormonal, neurológico y fisiológico(15). Los estudios sociales de la discapacidad han surgido en respuesta a este discurso autorizado de medicalización y han generado un cambio significativo en el horizonte de reconocimiento a estos grupos. Estos estudios han impulsado la definición de la discapacidad no como un “defecto físico”, sino como una forma de comprender estructuras opresivas. De este modo, la discapacidad se ha convertido en un sistema de representación más que un problema médico o una desgracia personal asociada a un cuerpo. En consecuencia, una discusión sociopolítica en torno a la realidad de las personas con discapacidad se ha potenciado para observar la vulneración de derechos, la invisibilización y las diversas formas

Tabla 1. Elementos interconectados en la competencia cultural de la discapacidad

Componentes	Dimensiones que involucra
1) Toma de decisiones biomédicas	Prácticas, políticas, leyes, educación y actitudes en relación con la discapacidad
2) Cultura e historia de la discapacidad	Conciencia, apoyo, desarrollo y promoción de la historia, la cultura, la cultura material y las artes de la discapacidad
3) Tecnología y diseño accesibles	Diseño, desarrollo y promoción de tecnología accesible basados en el usuario como condición para la calidad de vida de las personas con discapacidad.
4) Legislación sobre discapacidad y justicia social	Conocimiento y concientización de derechos legales, obligaciones, protecciones y beneficios de las personas con discapacidad.
5) Investigación de la competencia cultural de la discapacidad	Investigación en torno a la calidad de vida, el mantenimiento de la dignidad, el acceso y la autodeterminación.

Fuente: Construcción propia partir de(17).

de opresión a las que se somete a estos grupos(16).

En este sentido, Garland-Thompson sugiere dotar a los bioeticistas de lo que denomina “competencia cultural de la discapacidad”, que alude justamente a reconocer e incorporar el conocimiento en torno a las connotaciones sociales de la discapacidad. Para esta autora, “la competencia cultural de la discapacidad es un conjunto de habilidades o un conjunto de herramientas que todos necesitarán para navegar por la vida e implementar las promesas y obligaciones de las sociedades democráticas igualitarias”(17:332), interpretese también los derechos consagrados en la Convención. Esta competencia cultural involucra cinco elementos interconectados:

La discapacidad puede hacer que el trabajo de un bioético sea más útil, revelador, original y necesario. Pero las formas en que la discapacidad marca la diferencia son complejas, porque la discapacidad es un concepto escalar y multidimensional, que depende en gran medida del contexto más amplio. La experiencia de ser una persona con discapacidad es multifacética. Puede deberse a tener un diagnóstico particular o una limitación funcional consistente en no poder caminar ni oír bien. Puede que se trate de las barreras sociales a las que nos enfrentamos: el circuito auditivo que no funciona, la falta de rampa o ascensor. Puede que se trate de la falta de oportunidades sociales: la falta de seguro médico o de empleo. La experiencia de la discapacidad es el resultado de la interacción entre la persona con la condición de salud y el contexto social y cultural más amplio(18). Estas situaciones deben ser comprendidas por los bioeticistas en términos de “conciencia de la discapacidad”, como menciona Ouellette, reconociendo cuándo y cómo las percepciones sociales negativas sobre la discapacidad se infiltran en las decisiones médicas o en la formulación de políticas, o a la manera de Garland Thomson, como “competencia cultural” de la discapacidad. Ambas autoras aluden a la necesidad de generar prácticas informadas por la investigación y la consideración de la experiencia de las personas con discapacidad en primer lugar.

El objetivo apropiado entonces de la bioética de la discapacidad debe ser fortalecer los aspectos culturales, políticos, institucionales y de entorno

material en el que las personas con discapacidad puedan prosperar más eficazmente. Esta definición saca tanto la discapacidad como la bioética de un contexto principalmente médico o sanitario para expandir sus dominios a entornos materiales, instituciones cívicas, estructuras culturales e interacciones interpersonales(17).

Por otro lado, reconocer el poder distorsionador de la injusticia epistémica es de crucial importancia para la bioética de la discapacidad. Una de las funciones principales de la bioética es evaluar la permisibilidad ética de nuevas intervenciones y políticas de atención de salud. La discusión sobre la injusticia epistémica en los espacios de atención en salud sugiere que no es seguro asumir que los recursos de los que se valen los bioeticistas para hacer tales evaluaciones están a la altura del trabajo. De hecho, bioeticistas feministas han identificado que el conocimiento empírico y experiencial de las discapacidades que la bioética aporta a sus deliberaciones es inadecuado(6,19).

Considerar las experiencias vividas por las personas con discapacidad

Una bioética que incorpore el respeto por la diferencia y la aceptación de las personas con discapacidad como principio rector probablemente tendrá un compromiso más amplio que solo con otros académicos en el campo. Se comprometerá, ya sea como discurso académico o aplicación práctica, a refutar los argumentos que no respetan el valor de las personas debido a su condición de discapacidad. Pero incluso una bioética estrictamente interpretada como comprometida con la búsqueda del conocimiento y la comprensión con integridad se beneficiará al luchar con la evidencia de que las personas con discapacidad de manera persistente experimentan una calidad de vida buena o excelente, incluso cuando observadores desinformados puedan predecir lo contrario. La clave para la aplicación del principio de respeto en bioética es el conocimiento y la validación de las múltiples experiencias de discapacidad y el desarrollo de un debate inclusivo y bien informado sobre la vida con discapacidad(5).

Una bioética de la discapacidad debe implicar entonces más que simplemente prestar atención a ciertos focos de investigación empírica, la adop-

ción activa y la integración del análisis, la comprensión y la interpretación de las experiencias vividas por las personas con discapacidad(10). El campo de la bioética puede mejorar si abandona las generalizaciones sobre quiénes son las personas con discapacidad y cómo actúan, presentadas por narrativas dominantes opresivas, en favor de autodescripciones más matizadas que ofrecen las historias alternativas de las propias personas con discapacidad. Al desafiar estas narrativas maestras opresivas que limitan y distorsionan el significado social de la discapacidad, el activismo en materia de discapacidad puede mejorar la bioética dominante(8). Cuando a alguien se le presenta un argumento que se basa en premisas que contradicen ciertas narrativas ampliamente aceptadas, es probable que ese argumento sea descartado por absurdo. Esto le sucede regularmente a personas que ocupan posiciones sociales subordinadas, simplemente porque existe un sistema hermenéutico construido desde una posición social dominante: la “normalidad”. En consecuencia, muchas de las desventajas de la discapacidad son producidas por relaciones de poder opresivas que devienen de un capacitismo estructural(8) o de un sistema hermenéutico capacitista al que los grupos tradicionalmente subordinados deben “resistir”(20).

Los profesionales deben volverse expertos en los recursos hermenéuticos de las comunidades de personas con discapacidad y otras comunidades marginadas; y los médicos tienen la responsabilidad de reconocer la autoridad de las personas con discapacidad como expertos en sus propias vidas y comunidades, y de alzar sus voces. La medicina se ocupa de los procesos biológicos, no de los procesos de creación de significado de la vida humana tal como se vive realmente. El significado de una parálisis cerebral, por ejemplo, no se encuentra en los libros de texto de medicina: se encuentra escuchando a quienes viven con parálisis cerebral y a sus familiares(21).

Conclusiones

El presente artículo ha tenido como propósito realizar una contribución al campo de la bioética, y en particular a las discusiones epistemológicas en torno a una bioética de la discapacidad. Hemos propuesto tres dimensiones epistemológicas que, a nuestro juicio, resultan claves para una bioética informada de la discapacidad. En el tránsito hacia las dimensiones hemos indicado importantes desencuentros entre activistas, expertos en discapacidad y bioéticos que propician un ambiente de desconfianza, ruptura y miedo de parte de las personas con discapacidad.

Esta situación ha sido abordada en las dos últimas décadas de forma significativa, y en esta producción científica es posible reconocer algunas de las dimensiones epistemológicas que este trabajo presenta, y que tributan a una comprensión de la discapacidad que escapa al discurso médico capacitista, para situarse desde una mirada social y crítica que intenta brindar el marco para comprender las experiencias de las personas con discapacidad como diferenciadas y en ningún caso interpretables a partir de modelos médicos tradicionales de comprensión del bienestar y la buena vida, asentados en la “normalidad” como ideología opresiva que mina los recursos hermenéuticos colectivos.

Considerar la discapacidad desde una perspectiva de derechos humanos habilita discusiones relevantes sobre las connotaciones diferenciadas que debe tener la bioética cuando investigue o tome decisiones en torno a la vida y el uso de ciertos procedimientos biomédicos con personas con discapacidad. Por su parte, tener en cuenta el saber experto que emana de los estudios sociales y críticos de la discapacidad permite comprender el impacto social que el diagnóstico y el tratamiento médico o discursivo del personal de salud hacia los pacientes tiene en la vida de los sujetos y sus familias. Por último, considerar las experiencias de las personas con discapacidad como válidas evita la injusticia epistémica que se produce en intercambios médicos en donde solo se escucha la voz del profesional de la salud.

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THE ETHICAL PRINCIPLE OF RISK GOVERNANCE: ANALYSIS OF THE DEVELOPMENT OF THE PRECAUTIONARY PRINCIPLE

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Abstract: Modern society needs to be vigilant and respond promptly to risks. The emergence of uncertainties not only may increase the probability of risks occurring but also may exacerbate their severity. Therefore, what ethical principle should be relied on to deal with risks characterized by uncertainty has become a problem to be solved. The precautionary principle is an important ethical principle for addressing and resolving risks with uncertain features. This article aims to explain the changes of the precautionary principle in risk governance from its origin, the expansion of its geographical scope, and the increase in its application fields; and focuses on demonstrating the continuous improvement of the precautionary principle in risk governance through the transformation from the weak precautionary principle governance model with limited effectiveness to the strong precautionary principle governance model with high effectiveness.

Keywords: risks, uncertainty, precautionary principle, ethical governance

El principio ético de la gobernanza del Riesgo. Análisis de la evolución del principio de precaución

Resumen: La sociedad moderna necesita estar alerta y responder con prontitud a los riesgos. La aparición de incertidumbres no solo puede aumentar la probabilidad de que ocurran, sino también que se agraven. Por lo tanto, “qué principio ético debe aplicarse para hacer frente a los riesgos caracterizados por la incertidumbre” se ha convertido en un problema que hay que resolver. El principio de precaución es un principio ético fundamental para abordar y resolver los riesgos con características inciertas. El presente artículo tiene por objeto explicar los cambios del principio de precaución en la gobernanza del riesgo desde su origen, la ampliación de su ámbito geográfico y el aumento de sus campos de aplicación, y se centra en demostrar la mejora continua del principio de precaución en la gobernanza del riesgo, a través de la transformación del modelo de gobernanza del principio de precaución débil, con una eficacia limitada, al modelo de gobernanza del principio de precaución fuerte, con una alta eficacia.

Palabras clave: riesgos, incertidumbre, principio de precaución, gobernanza ética

O princípio ético da governança de riscos: Análise do desenvolvimento do princípio da precaução

Resumo: A sociedade moderna necessita ser vigilante e responder prontamente a riscos. A emergência de incertezas não somente aumenta a probabilidade de riscos ocorrerem como também podem exacerbar sua gravidade. Assim, qual princípio ético deve ser adotado para lidar com riscos caracterizados pela incerteza, tornou-se um problema a ser resolvido. O princípio da precaução é um princípio ético importante para abordar e resolver riscos com características incertas. Esse artigo objetiva expor as mudanças do princípio da precaução na governança de riscos desde sua origem, a expansão de sua abrangência geográfica e ao aumento em seus campos de aplicação; e concentra-se em demonstrar a contínua melhora do princípio da precaução na governança de riscos através da transformação de um fraco modelo de governança baseado no princípio da precaução, com eficácia limitada, para um forte modelo de governança baseado no princípio da precaução, com alta eficácia.

Palavras chave: riscos, incerteza, princípio da precaução, governança ética

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Introduction

Risks mainly refer to undesirable events that may or may not occur(1). Among these, the risks that may lead to a large number of casualties, significant economic losses, or extensive environmental damage deserve particular attention. With the rapid development of technology, especially the emergence of “technological convergence”(2) and the appearance of “uncertain” emerging technologies(3,4) with the potential to create new industries or transform existing ones(5), the risks and their potential negative impacts have become increasingly alarming.

The precautionary principle is an ethical principle that emerges along with risks. Its fundamental proposition is: In the presence of certain scientific uncertainties, precautionary measures should be taken. Its core demand is to avoid potential risks from evolving into actual harm in the future. We need to prevent the occurrence of harm from the very beginning. This principle can change along with the changes in risks and the demands for risk governance.

Due to the insufficient understanding of the concept of the precautionary principle by the public, some people have misunderstood it, questioning its effectiveness and opposing its application. This may delay the governance process, leading to delayed and flawed governance. Therefore, this article examines the origin of the precautionary principle, its application in different regions, its application in different fields, and the changes in its effectiveness, in order to enable people to understand how the precautionary principle continuously improves itself and functions in a risk society.

1. The origin of the precautionary principle

The origin of the precautionary principle can be traced back to the “no harm” principle in the Hippocratic Oath(6). In the 1950s, some people in the United States used a similar view to the precautionary principle to oppose fluoridation of water, and in the 1960s, others used similar arguments to oppose nuclear energy; they believed that high doses of fluoride or nuclear radiation had known adverse effects, and thus, if not used properly, could cause widespread harm(7).

The concept of the precautionary principle first emerged in a draft German bill aimed at ensuring clean air in 1970 (the bill was passed in 1974), and was then known as “Vorsorgeprinzip”. It was intended to reduce and limit environmental risks from a safety perspective or to protect and improve natural conditions by predicting future environmental conditions(8). The country’s 1976 Environmental Report and 1986 Environmental Precautionary Guidelines also adopted the precautionary principle as the guiding principle for its environmental policies(9). It can be said that Germany’s environmental policies have provided a relatively specific and comprehensive elaboration of the precautionary principle. By “relatively specific”, it means that the requirements of the precautionary principle are relatively clear. This principle divides human actions into those that cause harm and those that cause risks. For actions that cause harm, the government should take all measures to prevent them; for actions that cause risks, the government should conduct risk analysis and order precautionary measures when deemed appropriate. This principle provides a legitimate reason for the German government to intervene in the daily lives of states and citizens under the name of good governance, as well as to plan the economy, technology, morality, and society(10,11). By “relatively comprehensive”, it means that the content of the precautionary principle covers responsibility to future generations, comprehensive and simultaneous research, action before scientific conclusions, and the burden of preventing harm through technological progress. The principle states that “responsibility to future generations means protecting the natural basis of life and avoiding irreversible damage such as forest decline”, so “harm to the natural world (that is, the world on which we all depend for survival) should be avoided in advance based on opportunities and possibilities; to “discover dangers to health and the environment as early as possible through comprehensive and simultaneous research, especially research on cause and effect”; to “take action before scientific conclusions are reached”; to “develop technological processes in all economic sectors that can significantly reduce the environmental burden (especially those caused by the introduction of harmful substances)”(12).

Since the 1980s, the precautionary principle has gradually become an important component of governance policies. The process of continuously enriching the concept and application scope of the precautionary principle at successive “International Conferences on the Protection of the North Sea” marked the beginning of its gradual introduction to the international stage of risk governance. The “Declaration of the International Conference on the Protection of the North Sea” formed at the first “International Conference on the Protection of the North Sea” held in Bremen in 1984 proposed that “for the protection of the North Sea, precautionary measures to control air quality through reducing emissions at the source should be determined based on the best available technology” and “detailed plans should be developed to take precautionary measures in response to emergencies and accidents”, which was the embryonic form of the precautionary principle in international agreements(13). At the “Second International Conference on the Protection of the North Sea” held in London in 1987, the “Ministerial Declaration” proposed the “principle of precautionary action” or “precautionary approach” under the name of the precautionary principle; the governance characteristics of the precautionary principle, which limits harm or negative impacts from the source regardless of whether there is sufficient scientific evidence to prove the causal relationship between actions and hazards, and the construction of a hazardous substance handling approach with the characteristics of a precautionary path, were clarified(14). At the “Ministerial Declaration of the Third International Conference on the Protection of the North Sea” held in The Hague in 1990, the term “precautionary principle” first appeared in the series of North Sea protection conferences(15). In 1995, at the “Fourth International Conference on the Protection of the North Sea”, the “Esbjerg Declaration” formed there made the precautionary principle the guiding principle for achieving the goal of ensuring the sustainable, sound and healthy state of the North Sea ecosystem, further enhancing the principle’s status in environmental risk governance(16). In 2002, the “Bergen Declaration” formed at the “Fifth International Conference on the Protection of the North Sea” initially expanded the application scope of the

precautionary principle to the field of genetically modified organisms, and focused on addressing and responding to the “inherent, potentially serious, irreversible and transboundary impacts” resulting from the release of genetically modified organisms, thereby “ensuring that the cultivation of genetically modified marine organisms is restricted within a safe range”(17).

2. Expansion of geographical scope

The Convention for the Protection of the Marine Environment of the North-East Atlantic, also known as the OSPAR Convention, which was formed at the Ministerial Meeting of the Oslo and Paris Commissions, has a broader geographical scope than the previous International Conferences for the Protection of the North Sea, but the applicable fields are similar. Therefore, there is a certain degree of mutual reference in the understanding and application of the precautionary principle between the two. For instance, the OSPAR Convention defines the precautionary principle as: “When there are reasonable grounds for concern that the introduction of substances or energy into the marine environment, directly or indirectly, may cause harm to human health, damage biological resources and marine ecosystems, deteriorate environmental quality or interfere with legitimate uses of the sea, precautionary measures should be taken even in the absence of conclusive evidence of a causal relationship between the input and the effect.” This is similar to the definition of the precautionary principle in the Ministerial Declaration of the Second International Conference for the Protection of the North Sea(18). The Treaty on European Union, also known as the Maastricht Treaty, has expanded the geographical influence of the precautionary principle from the North Sea and the North-East Atlantic to the entire European Union, and it can be applied in fields such as the environment, public health, and consumer protection(19). It also combines the goal of “a high level of protection” and the consideration of “the diversity of situations in different regions within the Community” with the precautionary principle(20).

Apart from Europe, other countries and regions around the world have also adopted the precautionary principle as an important principle of

national or regional policies, further expanding its influence. For instance, the Bamako Convention on the Ban of the Import into Africa and the Control of Transboundary Movement and Management of Hazardous Wastes within Africa, or simply the Bamako Convention, marks an important beginning for many African countries to apply the precautionary principle to address the threat of hazardous waste. The convention recognizes that the volume of hazardous waste is constantly increasing and that its complexity poses an increasingly serious threat to human health and the environment. Therefore, it proposes that "Parties shall strive to adopt and implement precautionary approaches to address pollution problems, including but not limited to preventing the release of substances that may cause harm to human health or the environment before scientific evidence of such harm is obtained" and "Parties shall cooperate and take appropriate measures to implement the precautionary principle through the application of clean production methods to prevent pollution, rather than pursuing methods that allow emissions based on the assumption of environmental self-purification capacity", and urges the contracting parties to effectively manage and restrict the cross-border transportation of hazardous waste in Africa(21). In the United States, precautionary thinking is also at play, with severe and irreversible harm being prioritized for precaution. For example, the "Precautionary Principle Ordinance" proposed by the San Francisco Board of Supervisors - which later evolved into "The San Francisco Precautionary Principle" in the San Francisco Environment Code(22): "In the presence of a threat of serious or irreversible harm to human health or the natural environment, the lack of full scientific certainty about cause and effect shall not be used by the City as a reason for postponing cost-effective measures to prevent environmental degradation or protect the health of its citizens"(23). Since then, San Francisco has become the first local government in the United States to clarify and implement the precautionary principle, providing a new path for the city to formulate and implement laws and policies related to health and the environment.

The Rio Declaration on Environment and Development, also known as the Rio Declaration,

for the first time expanded the geographical scope of the precautionary principle to the global level, making it a universal principle. Moreover, the declaration set "the threat of serious or irreversible harm"(24) as the premise for the widespread adoption of precautionary measures, enabling countries to protect human health and the ecological environment while also considering prudent development. The United Nations Framework Convention on Climate Change and the Convention on Biological Diversity, both adopted in the same year, also contributed to the globalization of the precautionary principle. The United Nations Framework Convention on Climate Change stipulates that "each Party shall take precautionary measures to predict, prevent or minimize the causes of climate change and mitigate its adverse effects."(25) Although the Convention on Biological Diversity does not directly use the term "precautionary principle," its content reflects the precautionary thinking that measures should be taken to avoid significant reduction or loss of biodiversity in the face of serious and irreversible harm with scientific uncertainty(26).

3. Expansion of Applicable Fields

The above-mentioned countries, regions and international treaties, while introducing the development of the precautionary principle, focus on demonstrating its continuous expansion in geographical scope and mainly concentrate on the environmental field (a considerable part only incidentally touches upon public health, genetically modified organisms, consumer protection and other fields), while the following policies and treaties show that the precautionary principle plays a major role in more fields.

The Cartagena Protocol on Biosafety, by emphasizing that the contracting parties should be aware that "modern biotechnology is developing rapidly, and the public is increasingly concerned about its potential adverse effects on biodiversity, as well as the risks it poses to human health" and that "if modern biotechnology is developed and utilized under adequate safeguards for the environment and human health, it will have great potential for human well-being", thus "reaffirms the precautionary approach as set out in the Rio Declaration on Environment and Development",

has thoroughly extended the focus and application of the precautionary principle to the field of biotechnology. At the same time, the Cartagena Protocol on Biosafety, based on the precautionary principle, “addresses issues such as biodiversity and biosafety (protecting human health and the environment from potential adverse effects of modern biotechnology products), and provides a comprehensive and holistic approach for the conservation of biodiversity, the sustainable use of natural resources, and the fair and equitable sharing of benefits arising from the utilization of genetic resources”(27), significantly enhancing the status of the precautionary principle in the governance of biotechnology. Additionally, the Stockholm Convention on Persistent Organic Pollutants, which aims to protect human health and the environment from chemical substances and strengthen the management of chemicals, incorporates chemicals, especially toxic and harmful ones, into the application objects of the precautionary principle(28). Similar to the Cartagena Protocol on Biosafety, this convention is also influenced by the Rio Declaration, taking the precautionary principle in the Rio Declaration as the benchmark for chemical governance. It is particularly worth noting that this convention is one of the earlier international treaties to link scientific uncertainty with the precautionary principle.

If the Rio Declaration made the precautionary principle a universal principle, then the report named “The Precautionary Principle” formulated by the World Commission on the Ethics of Scientific Knowledge and Technology of UNESCO has made it a truly multi-field universal principle. The report states that “when human activities may cause morally unacceptable harm, and such harm is scientifically possible but not yet certain, actions should be taken to avoid or mitigate such harm; morally unacceptable harm refers to harm to humans or the environment that threatens human life or health, or is serious and actually irreversible, or is unfair to the present or future generations, or is imposed without fully considering the human rights of those affected”(29). This “working definition” creatively shifts the trigger for precautionary measures from direct harm or harmful effects to morally unacceptable harm. This not only more closely links the precaution-

ary principle with ethics but also constrains the triggering and application of restrictions and bans in precautionary measures within a reasonable range, thereby facilitating scientific and technological development and social progress.

Since the promulgation of the above-mentioned treaty until today, there have been countless declarations, guidelines, policies and regulations applying the precautionary principle to specific fields such as medical research and development, infectious disease prevention and control, artificial intelligence, autonomous driving, and synthetic biology, making the precautionary principle a significant ethical principle in the world and making precautionary thinking and approaches generally the basis and starting point of policymaking. However, the specific expressions of the precautionary principle in various policies are diverse and complex, sometimes making it difficult for people to clearly understand it and even leading to misunderstandings. Therefore, it is necessary to analyze them by type and weigh them in application.

4. Changes in governance models

4.1 Limited governance of the weak precautionary principle

The weak precautionary principle is an early version of the precautionary principle (it even predates the prior principle and became the main target of criticism for the prior principle). Although this version is still occasionally invoked today due to its certain rationality, its limited governance effectiveness has hindered its application in the governance of emerging technology risks.

4.1.1 Pay attention to potential serious and/or irreversible risks

One of the characteristics of the weak precautionary principle is its focus on potential serious and/or irreversible risks. This is exemplified by the precautionary principle mentioned in the “Meeting on Sustainable Development” held by the Economic Commission for Europe (ECE). It states: “To achieve sustainable development, policies must be based on the precautionary principle. Environmental measures must anticipate,

prevent, and eliminate the root causes of environmental degradation. In the face of a threat of serious or irreversible harm, measures to prevent environmental degradation must not be postponed on the grounds of scientific uncertainty”(30).

Although the above-mentioned policies have touched upon severe and irreversible harm, it was Cass R. Sunstein who refined and theorized them. Sunstein’s “Catastrophic Harm Precautionary Principle” states that when catastrophic consequences are possible, special precautionary measures should be taken to deal with the worst-case scenario(31). This principle requires people to be aware of the underestimation and cognitive lag of catastrophic harm (possibly due to the “availability heuristic” and “scope neglect” theories mentioned when discussing survival risks), and thus calls for precaution in advance. Emphasizing precaution in advance is a common feature of any precautionary principle, which is in line with the forward-looking governance of emerging technology risks and is reasonable. Additionally, Sunstein, based on this principle, pointed out that risks can be divided into risks with known probabilities of possible consequences (narrowly defined risks) and risks with unknown probabilities of possible consequences (which he called uncertainties), and focused the governance concern of the precautionary principle on risks with unknown probabilities of possible consequences. This limited scope of concern will result in a limited scope of risk governance, thereby affecting the effectiveness of the precautionary principle in risk governance. Sunstein’s “Irreversible Harm Precautionary Principle” emphasizes that regulatory agencies can choose to postpone decisions when lacking information on the possibility and severity of risks to prevent irreversible harm(32). This principle proposes an important preventive measure, that is, to suspend the application process and wait for scientific research to increase the scientific information available for risk-benefit assessment. This measure can effectively prevent the occurrence of risks, but due to its singleness, it lacks flexibility in responding to risks.

4.1.2 Emphasize the cost-benefit trade-off

Emphasizing the cost-benefit trade-off is also a characteristic of the weak precautionary prin-

ciple. A typical example of this feature is the weak precautionary principle included in the environmental policies issued by the UK Department for Environment, Food and Rural Affairs. While focusing on the “significant risk of major harm”, this principle also stresses the importance of considering the cost of measures and tends to adopt a cost-benefit analysis approach.

To ensure that precautionary measures are commensurate with the likelihood of risks occurring, this principle distinguishes between two scenarios: “scientific knowledge is not yet conclusive” and “there are sufficient grounds to judge”, along with corresponding countermeasures. For the former scenario, the countermeasure is “as long as the cost-benefit analysis indicates it is reasonable, we can take precautionary measures to limit the spread of potentially hazardous materials or pollutants”; for the latter scenario, the countermeasure is “promptly take relatively low-cost actions to avoid potential greater harm in the future”(33).

The commonality of the two countermeasures lies in their use of the cost-benefit trade-off approach. The advantage of this approach is that it can minimize the occurrence of potential risks with low probability and/or low severity, causing widespread panic in society, as well as prevent the waste of human, material, and financial resources due to disproportionate precautionary measures compared to the actual risk level. The difference between the two countermeasures is that the latter is timely, while the former is lagging. The reason is that the logic of this countermeasure is to obtain sufficient scientific knowledge first, then make a trade-off based on that knowledge, and then take proportionate actions; if the scientific knowledge is insufficient, the actions cannot be implemented. For emerging technologies with uncertainties, specific cases with sufficient scientific knowledge can easily conduct cost-benefit trade-offs and take corresponding countermeasures; however, for specific cases with high scientific uncertainty, the practical effect of cost-benefit trade-offs is rather limited. Therefore, although emphasizing the trade-off is reasonable in general, in the governance of emerging technology risks, this method has limitations in its scope of application.

4.1.3 Emphasizing that the regulator bears the burden of proof

The third characteristic of the weak precautionary principle is that it places the burden of proof on the regulator rather than the regulated. Under this conception of the weak precautionary principle, the burden of proof lies with the regulatory body, which is responsible for envisioning potential harms and taking regulatory actions in advance; meanwhile, developers of new technologies do not need to prove that their technologies will not have negative impacts⁽³⁴⁾. The advantage of this feature is that it saves the energy of the developers and converters of new technologies, reduces their burden, builds a more relaxed relationship between regulators and the regulated, and is conducive to the accelerated development of emerging technologies in a more lenient regulatory environment.

However, it is unreasonable to place the burden of proof on regulators. One reason is that the number of technological research and development activities is huge, while the number of regulators is extremely limited. If the number of regulators is blindly expanded to cope with the numerous technological research and development activities and to identify specific matters with risks from the details of the research and development process, it will lead to excessively high governance costs and make regulatory activities unsustainable. The second reason is that the knowledge background of regulators may not match the rapidly evolving cutting-edge technological research and development activities. For some rapidly developing emerging technologies, only the researchers themselves have a better understanding of the potential risks involved. The third reason is that some regulated entities may conceal or disguise their technological activities, making it impossible for regulators to actually bear the burden of proof, as they may not be able to obtain genuine and effective information and data about the technological research and development activities, and thus cannot make evaluations and decisions.

Overall, the weak precautionary principle focuses on potential severe and/or irreversible risks and emphasizes the cost-benefit trade-off. These two

characteristics have a certain rationality. However, the weak precautionary principle with these two features can only deal with risks with known probabilities of occurrence, but cannot effectively respond to risks with scientific uncertainties promptly, thus having certain limitations in the governance of emerging technology risks. In addition, the requirement for regulators to bear the burden of proof under the weak precautionary principle cannot be achieved due to the diversity, complexity and uncertainty of knowledge in emerging technologies. However, the weak precautionary principle is still a type of precautionary principle, and thus has the forward-looking governance goal that is common to all precautionary principles. From this perspective, it has already surpassed the traditional lagging risk governance principles.

4.2 Effective governance under the strong precautionary principle

Compared with the weak precautionary principle, the strong precautionary principle has a stronger effect on risk governance. This enhanced governance effect is achieved through a more explicit division of responsible subjects and types of responsibility under this principle, as well as a more proportionate risk governance mechanism.

4.2.1 Clear responsibility subjects and types

The strong precautionary principle advocated by Noah M. Sachs, Frida Kuhlau, and others has made significant contributions to clarifying the responsible subjects and types.

Frida Kuhlau and others have proposed that both the regulated and the regulators should bear corresponding responsibilities. First, the regulated are the main bearers of the burden of proof; that is, the scientific community and individual participants have the responsibility to conduct information retrieval and prove, based on the retrieved information, that their research is not related to the assumed threats. Whether the responsibility should be borne by individual researchers or by the scientific community or the entire scientific field depends on the specific circumstances (for example, when expressing concerns about the intentions of a peer's research project, the indi-

vidual has the responsibility to bear the burden of proof; while in the risk review of dual-use technologies, the scientific community or the entire scientific field should bear the burden of proof). Second, the regulators have both the burden of proof and the responsibility for action. On the one hand, they need to provide information to prove that the risk is credible, and on the other hand, they need to take actions (i.e., precautionary measures) to respond effectively(35).

Here, there is a sequence in the burden of proof for researchers and regulators. Researchers should take the lead in shouldering the burden of proof, and the burden they bear is heavier. This is because the scientific uncertainty of emerging technologies means that regulators have access to information about emerging science much later than researchers on the front lines. In other words, regulators' understanding of emerging technologies depends on researchers' disclosure of information about emerging technologies. However, if researchers, as the regulated party, bear the burden of proof alone, it may affect their normal research progress. Therefore, the intervention and participation of regulators are needed.

The manifestation of the regulator's responsibility for action is to take precautionary measures to deal with risks. There are two bases for determining what precautionary measures to take. One is the "severity of the risk as a necessary prerequisite for taking precautionary measures"(36) proposed by Noah M. Sachs in his strong precautionary principle. That is to say, it is necessary to set up a "serious risk threshold" in advance, and based on the ratio of the risk level to the threshold, determine the implementation of precautionary measures, including comprehensive bans, restrictions, labeling and warning requirements, etc. Another approach is the "thresholds of seriousness and credibility" method proposed by Kuhlen et al. This method scientifically compares the severity and credibility of risks related to knowledge, technology, materials, etc. with the set thresholds, and takes commensurate precautionary measures based on the size of the ratio to the threshold. Among them, for risks that are less severe and less likely to occur compared to the threshold, the main responsibility of the regulator is to establish a risk awareness improvement mechanism and

encourage scientists to understand the outside world's concerns about technological risks; for risks that are more severe and more likely to occur compared to the threshold, the responsibility of the regulator is to call on and supervise a small number of scientists engaged in dangerous technology research to take greater cautionary responsibilities(37,38). It is not difficult to see that the latter is more conducive to regulators truly shouldering the responsibilities they should bear. The reason lies in that the latter places the credibility (i.e., the possibility of risk occurrence) on an equal footing with the severity, thus avoiding paying excessive and unnecessary governance costs due to "speculative concerns". This makes the extent of precautionary measures not only commensurate with the severity of the risk but also with the degree of uncertainty of the risk; thereby reasonably covering the entire range of emerging technology risks and "treating the right disease", preventing the situation where governance measures do not match the degree of risk.

In addition to the burden of proof and the responsibility for actions, Sachs also proposed that regulators should assume the role of "risk gatekeeper" and "decider". He assigned regulators the roles of "risk gatekeeper" and "decider". The responsibility of the "risk gatekeeper" is, on the one hand, to urge the supporters of actions or products to assume the burden of proof and conduct thorough research to prove the safety of the technology, thereby minimizing risks; on the other hand, it is to conduct "risks review" and "risk assessment" before actions with potential risks start or before products with potential risks enter the market - identifying which risks are serious and worthy of regulation. The responsibility of the "decider" is to determine whether the supporters of actions or products have fulfilled the burden of proof for verifying the safety of the actions or products(39).

Overall, the responsibility of researchers comes first, while that of regulators takes precedence. This division of responsibility and allocation of duties can not only give due attention to the scientific uncertainty characteristics of emerging technologies and ensure the safety of scientific research activities; but also minimize the burden on researchers and provide a relatively relaxed envi-

ronment for scientific research, thereby ensuring the healthy development of emerging technologies.

4.2.2 Proportional risk management

Proportional risk governance is also known as proportionate risk governance. Proportionality is an important feature of the principle of the strong precautionary principle. It can expand the scope and effectiveness of this principle. The proportionality of the strong precautionary principle has two meanings. One meaning is that the precautionary measures envisioned and taken should be commensurate with the expected level of protection, that is, the actor adjusts the measures according to the selected protection level(40); the other meaning is that the precautionary measures should be commensurate with the severity of the risk and the possibility of its occurrence(41).

Regarding the so-called “expected level of protection” in the first meaning, it should be noted that when dealing with emerging technologies, blindly pursuing zero risk is unrealistic. The first reason is that technological progress is always accompanied by risks, and there are no completely risk-free technological research and development activities; the second reason is that the extreme pursuit of approaching zero risk may require excessive human and material resources, and such a pursuit is not sustainable. Therefore, what “expected level of protection” that aims to achieve is risk control and appropriate protection. The situation of risk control and appropriate protection can fundamentally be regarded as not causing survival risks to humans, that is, not causing serious and irreversible impacts on human survival and development. When the universal goal faces specific emerging technology research and application, it can be set more specifically based on this universal goal and the relevant scientific information of the specific technology. For the so-called “designed and adopted precautionary measures” in the first meaning, it should be noted that complete prohibition may be one of the feasible methods to deal with potential risks, but it is not the only method. Other specific precautionary measures include taking restrictions, strengthening control, reducing exposure, adopting temporary limit values, providing advice to

high-risk groups, using safer research procedures or products for substitution, etc.

If the first layer of proportionality sets the macro framework for risk governance for the strong precautionary principle, then the second layer of proportionality gives the direct requirements for risk governance for this principle. The most in line with the direct requirements of proportionality is Per Sandin’s strong precautionary principle. Sandin’s precautionary principle emphasizes: if there is a threat and this threat is uncertain, then some compulsory action must be taken; the analysis of specific matters and their precautionary measures should be conducted in four dimensions: threat, uncertainty, command and action(42).

The “threat” in the dimension of threat mainly refers to a certain undesirable state that is caused by humans and may occur. The judgment of the size of the threat generally includes the severity (whether it is severe or not), reversibility (reversible or irreversible), and preventability (preventable or not preventable)(43). The “uncertainty” in the dimension of uncertainty refers to the state of our understanding or lack of understanding of possible world states. The judgment basis of the size of uncertainty is the level of our understanding of a certain action or product, that is, the reasonable degree of the risks disclosed by scientific evidence (the accuracy of the risks disclosed by scientific evidence). The lower the accuracy, the higher the uncertainty. The “command” in the dimension of instructions is also called regulations. These instructions can be classified into allowable, reasonable, recommended, and mandatory based on the degree of mandatoryness. The “action” in the dimension of action refers to what actions to take to respond to the threat, and the division of action caution and leniency is based on the scope of taking actions. The broader the scope of action, the more cautious it is, and the opposite indicates a more lenient situation. From this, it is easy to see that the requirement of “the risk governance means being commensurate with the severity and/or the possibility of risk occurrence” as proposed by Sandin is reflected in “the instructions and actions being commensurate with the threats and uncertainties”, thereby making the flexibility and operability of the precautionary principle in risk governance stronger.

Conclusion

Appropriate risk governance is a prerequisite and important guarantee for the stable development. How to handle the potential risks and safeguard the reasonable interests and development potential of both the current and future generations is of vital importance to the survival and prosperity of humanity.

Although the precautionary principle is generally forward-looking, not all precautionary principles are effective in the risk governance of emerging technologies. The limitations of the weak precautionary principle in terms of governance scope lead to its deficiency in effectiveness, thus making it not fully applicable. Critically inheriting the reasonable features of the weak precautionary principle and further developing the strong precautionary principle, which has a wide governance scope, flexible governance measures,

clear responsibilities, and strong operability, is more in line with the demands of contemporary risk governance characterized by rapid development and obvious uncertainty. In conclusion, strong precautionary principle is one of the important ethical principles in contemporary risk governance. Formulating corresponding norms, targeted guidelines and policies in combination with this ethical principle and specific real-world circumstances is the key next step to effectively control risks and ensure the stable development of society.

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THE CRIMINAL LAW REGULATORY LOGIC AND FUTURE PATHWAYS OF GENE EDITING TECHNOLOGY IN CHINA: SEVEN YEARS AFTER “GENE-EDITED BABIES”

Li Zhenkang¹

Abstract: The 2018 “gene-edited babies” incident marked a critical turning point in China’s criminal regulation of gene editing. Before the incident, China largely relied on administrative rules and ethical guidelines to govern gene-editing activities, without a systematic criminal legal framework or comprehensive regulatory mechanisms. In the aftermath, China intensified its efforts to establish stronger legal controls over gene-editing technology. This study examines the regulatory landscape seven years after the event, integrating empirical data on public awareness and perceptions of gene editing with a literature-based legal analysis of the current legislative framework and its deficiencies. Through this dual approach, the paper aims to deepen understanding of the evolution of China’s criminal regulation of gene editing and to provide policy insights for China and other developing countries seeking to strike a balance between scientific innovation and ethical as well as legal accountability.

Keywords: gene editing technology, criminal regulation, ethical issues, China

La lógica reguladora del Derecho Penal y las perspectivas futuras de la tecnología de edición genética en China: siete años después de los “bebés editados genéticamente”

Resumen: El incidente de los “bebés editados genéticamente” en 2018 marcó un punto de inflexión crucial en la regulación penal de la edición genética en China. Antes del incidente, China dependía en gran medida de normas administrativas y directrices éticas para regular las actividades de edición genética, sin un marco legal penal sistemático ni mecanismos regulatorios integrales. Tras el incidente, intensificó sus esfuerzos para establecer controles legales más estrictos sobre la tecnología de edición genética. Este estudio examina el panorama regulatorio siete años después del incidente, integrando datos empíricos sobre la concienciación pública y las percepciones de la edición genética con un análisis legal basado en la literatura del marco legislativo actual y sus deficiencias. A través de este doble enfoque, el artículo busca profundizar en la comprensión de la evolución de la regulación penal de la edición genética en China y proporcionar perspectivas políticas para China y otros países en desarrollo que buscan lograr un equilibrio entre la innovación científica y la responsabilidad ética y legal.

Palabras clave: tecnología de edición genética, regulación penal, cuestiones éticas, China

A lógica regulatória do direito penal e os caminhos futuros da tecnologia de edição gnetética na China: sete anos após os “bebês gneteticamente modificados”

Resumo: O incidente “bebês geneticamente modificados” marcou um ponto de virada na regulação penal da China sobre edição genética. Antes do incidente, a China dependia em grande parte de regras administrativas e diretrizes éticas para controlar atividades de edição genética, sem um arcabouço legal penal sistemático ou mecanismos regulatórios abrangentes. Após o ocorrido, a China intensificou seus esforços para estabelecer controles legais mais fortes sobre a tecnologia de edição genética. Esse estudo examina o cenário regulatório sete anos após o evento, integrando dados empíricos sobre conscientização e percepções do público em relação à edição genética com análise legal baseada na literatura do arcabouço legislativo atual e suas deficiências. Através dessa abordagem dual, esse artigo objetiva aprofundar a compreensão da evolução da regulação penal da China sobre edição genética e fornecer insights sobre políticas para a China e outros países em desenvolvimento buscando encontrar um equilíbrio entre inovação científica e a responsabilidade ética e legal.

Palavras chave: tecnologia de edição genética, regulação penal, questões éticas, China

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1. Introduction

The emergence of gene editing technology is widely regarded as a revolutionary breakthrough in the field of life sciences. It not only brings new hope for overcoming genetic diseases, improving treatment outcomes, and enhancing overall human health, but also opens up broad prospects for agricultural improvement and pharmaceutical development (1). With the advancement of AI, the integration of gene editing and intelligent algorithms is expected to significantly enhance research efficiency and accelerate profound transformations in medicine and life sciences (2). However, technological innovation often comes with risks. While benefiting humanity, it may also give rise to ethical dilemmas and safety concerns. For example, any error in germline gene editing could be transmitted across generations through heredity, leading to irreversible consequences, whereas human cloning and interspecies genetic chimeras could challenge the very foundations of human identity and ethical boundaries (3).

In China, the development of gene editing technology has also aroused widespread concern. The exposure of the “gene-edited babies” incident in 2018 not only shocked the academic community and the public at home and abroad but also pushed the conflict between the frontiers of life sciences and ethical boundaries to the center of public debate(4). In the aftermath, the Chinese government quickly took steps to strengthen criminal regulation, as it became increasingly clear that ethical review and administrative regulations alone were insufficient to provide effective constraints, and that criminal law should extend its reach to the domain of human gene editing(5). In response to public concerns, the *Amendment (XI) to the Criminal Law of the People's Republic of China* urgently introduced two offenses related to human genetic science—the crime of illegally carrying out human gene editing, cloning, and other reproductive medical activities, and the crime of illegally collecting or providing human genes, embryos, and other resources—thereby, to a certain extent, filling the legal gap in the criminal regulation of the abuse of human genetic technologies(6).

Time flies—seven years have passed since the

“Gene-Edited Babies” incident. This study seeks to address several key questions: What insights can empirical research on gene-editing technology, particularly in relation to the “Gene-Edited Babies” incident, provide? What is the current state of China’s legislative framework on gene editing, especially in terms of criminal regulation? And what deficiencies persist within the existing legal system governing gene-editing technology? The paper will systematically explore and analyze these issues to contribute to a deeper understanding of the legal and ethical governance of gene-editing in China.

2. Exploring the Reasons for the Criminalization of Gene Editing Technology

2.1 Gene Editing Technology Holds a Pivotal Strategic Position in China

Gene editing technology, as a revolutionary tool in the life sciences, has been assigned a highly strategic position in China. It is not only a core area of competition in cutting-edge science and technology but is also regarded as a key means to drive medical revolutions, ensure food security, and enhance the competitiveness of the bioeconomy (7). In 2016, the *National Innovation-Driven Development Strategy Outline* first proposed achieving breakthroughs in fields such as genomics and precision medicine(8). In 2020, *Biosecurity Law* further emphasized the safe governance and regulated development of biotechnology, including gene editing(9). In 2021, the Chinese central government, through top-level designs such as the *14th Five-Year Plan for Bioeconomy Development*, explicitly identified gene editing as a strategic scientific and technological direction and allocated substantial resources, aiming to achieve high-level technological self-reliance and secure a commanding position for future development(10). It can be seen that China’s strategic positioning is reflected in three main aspects:

- Treating gene editing as a critical technology for safeguarding national health and food security.
- Using it as an important driver of the bioeconomy and emerging industries.

- Leveraging it as a crucial asset for participating in global science and technology governance and Regulation formulation.

2.2 The application of gene editing technology has been advancing by leaps and bounds

China has taken a leading role in gene editing applications across multiple fields. In medicine, it launched the world's first human CRISPR clinical trial in 2016 and has since advanced both basic research and clinical trials, from studying cancer and genetic disorders to testing therapies for leukemia, lymphoma, B-thalassemia, and Duchenne muscular dystrophy (11). In agriculture, researchers use gene editing to improve rice, wheat, and corn for pest resistance, drought tolerance, and soil adaptability, while also enhancing livestock such as pigs resistant to African swine fever (12). In the industry, biomedical companies are rapidly investing in gene and cell therapies as well as molecular diagnostics, accelerating the commercialization of research and strengthening China's position in the global biomedical sector.

2.3 The Ethical Controversies Brought by Gene Editing Cannot Be Ignored

2.3.1 Hidden Genetic Discrimination

According to statistics, between 2000 and 2011, Chinese courts heard a total of 92 cases involving anti-discrimination claims, which were mainly concentrated in several categories. Among them, cases of discrimination against hepatitis B virus carriers were the most numerous, with 41 cases, accounting for 44.6% (13). This was followed by 9 cases of disability discrimination (9.8%), 8 cases of gender discrimination (8.7%), and 7 cases each of discrimination based on social origin and health status (7.6% each). In addition, there were 5 cases each of height discrimination and childbirth discrimination (5.4%), 4 cases of discrimination against HIV carriers (4.3%), 2 cases each of age discrimination and appearance-based discrimination (2.1%), as well as 1 case of regional discrimination and 1 case of employment discrimination caused by carrying pathogenic genes. Overall, discrimination against hepatitis B carriers dominated anti-discrimination cases, while genetic discrimination, though appearing

in only one case, already reflected the emergence of a new type of discrimination. Although there was just a single case of employment discrimination caused by carrying pathogenic genes among the 92 anti-discrimination cases, its significance goes far beyond the number itself. It not only reveals the potential of genetic information to become a new tool of discrimination but also reflects the lag in legal responses to emerging social risks brought about by technological development. As a concealed and forward-looking form of discrimination, genetic discrimination is gradually becoming a key area that future anti-discrimination law needs to address.

Gene-editing technology, while driving medical progress and disease prevention, also carries the potential risk of intensifying genetic discrimination (14). On the one hand, advances in gene editing have made genetic testing more sophisticated, making access to personal genetic information increasingly convenient. The misuse of such information could lead employers, insurance companies, or even educational institutions to treat individuals differently based on whether they carry certain genetic defects or have undergone genetic editing interventions, thereby infringing upon their rights to equality and privacy (15). On the other hand, the notion of "optimizing humanity" promoted by gene editing may fuel an excessive societal pursuit of "healthy" or "perfect" genes, which in turn could marginalize individuals who have not undergone genetic editing or who carry particular mutations. This not only reinforces inequalities in the distribution of social resources but may also, in subtle ways, create new forms of social stratification and discrimination.

2.3.2 Erosion of Social Equity and Fair Resource Distribution

Social equity represents an important value orientation of governance modernization in China, yet the development of gene editing technology may pose challenges to this goal. First, as a frontier technology with high costs and significant technical barriers, gene editing—if primarily controlled by a small group of elites or high-income classes—will lead to inequality in access and application (16). Such inequality is not only reflected in disparities in treatment opportunities but may also

generate intergenerational advantages through “genetic optimization,” thereby creating a “genetic divide.” Second, once this divide becomes entrenched, it may intensify existing social stratification and run counter to China’s current policy orientation of “common prosperity” (17). More seriously, if gene editing exerts implicit influences in areas such as education, employment, and social security, social stratification may acquire “technological” characteristics, resulting in entrenched and irreversible institutional inequality.

2.3.3 Risks to Ethnic Unity

The development of gene editing technology may provide individuals or groups with opportunities for “genetic optimization” based on hereditary traits (18). However, if access to this technology is distributed unequally, there is a risk of discrimination against specific groups or “non-optimized” individuals, thereby invisibly exacerbating inequalities both within and between ethnic groups. In China, ethnic unity and social harmony are regarded as fundamental pillars of national development. If gene editing is misused to promote evaluations of genetic “superiority” or to prioritize certain ethnic traits, it could not only undermine a sense of national identity but also weaken social cohesion, ultimately generating profound social and ethical challenges.

3. Empirical Analysis Regulatory Framework of Gene Editing Technology, and Exposed Issues

The year 2018 marked a pivotal point in the legal regulation of gene editing in China. In that year, He Jiankui announced the birth of the world’s first gene-edited babies, triggering widespread attention and ethical controversy both domestically and internationally, and exposing the existing legal gaps and regulatory deficiencies in China’s gene editing field (19). Therefore, this paragraph takes 2018 as a key node to examine the changes in relevant legislation before and after that year, and analyzes, based on survey data, the issues that still exist in the current application of gene editing technology in China.

3.1 Empirical Analysis on Public

A total of 1,200 questionnaires were distributed in this study, of which 1,080 (N=1080) were deemed valid, resulting in a valid response rate of 90%. The gender distribution was evenly balanced, with 540 males (50%) and 540 females (50%). Regarding educational attainment, Figure 1 presents that 216 participants (20%) had a high school education or below, 270 (25%) held an associate degree, 432 (40%) possessed a bachelor’s degree, and 162 (15%) had a master’s degree or above. This diverse sample composition ensures representativeness across gender and educational backgrounds, thereby providing a robust basis for analyzing variations in public awareness and attitudes toward gene-editing technology and related ethical and legal issues.

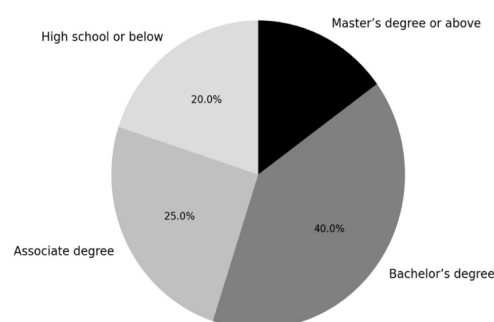


Figure 1: Educational Attainment of Respondents (N=1080)

To further verify this Correlation, data from Figure 2 demonstrate a clear upward trend in awareness with increasing education level. Specifically, only 30% of respondents with a high school education or below had heard of gene editing technology, compared with 40% among junior college graduates, 50% among those with a bachelor’s degree, and as high as 93% among master’s degree holders. Similarly, awareness of the He Jiankui gene-edited babies incident increased from 12% in the lowest education group to 44% in the highest. These results indicate that education level is a key determinant of public understanding of scientific and ethical issues: individuals with higher education not only possess greater exposure to scientific information but also

tend to adopt more rational and balanced attitudes toward emerging biotechnologies. Therefore, strengthening bioethics and science communication—particularly among groups with lower educational attainment—remains essential for fostering informed social dialogue and responsible public engagement.

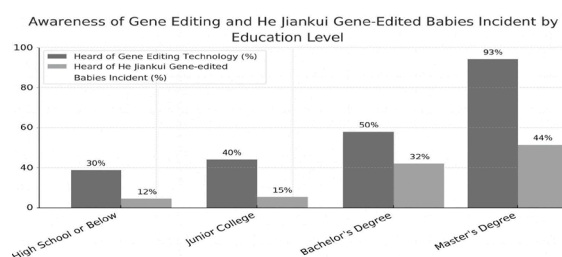


Figure 2: Empirical Research Data on Gene Editing Technology and the Gene-Edited Babies Incident

3.2 Legislative Changes Regarding Gene Editing Technology

Before 2018, China primarily relied on administrative regulations and ethical guidelines in the field of gene editing, such as the *Interim Measures for the Administration of Human Genetic Resources* (1998) and the *Ethical Guidelines for Human Embryonic Stem Cell Research* (2003), lacking clear criminal liability and a systematic regulatory framework². The He Jiankui gene-edited babies incident prompted the advancement of criminal legislation on gene editing in China, namely the *Criminal Law Amendment (XI)* (20). There are currently two offenses in Chinese criminal law related to human genetic technology: first, the crime of illegally collecting human genetic resources or smuggling human genetic material; and second, the crime of illegally implanting gene-edited or cloned embryos (21).

However, despite the criminal law clearly defining the scope of punishment and legal responsibility, numerous problems remain (22). First, the legal provisions do not fully keep pace with the rapid development of gene-editing technologies (23). New experiments such as CRISPR are constantly emerging, while the law's revision cycle is relatively

long, making certain behaviors difficult to clearly define (24). Second, the connection between criminal law and ethical review is insufficient. Overreliance on criminal sanctions may stifle scientific innovation, while ethical review alone is often inadequate to effectively prevent high-risk activities. Third, enforcement and judicial application face significant challenges. Gene editing involves highly specialized experiments and data, making evidence collection difficult, and the dispersed oversight by multiple departments can lead to regulatory gaps or duplicate penalties. Finally, there are obstacles to international coordination and cross-border governance. China's criminalization standards differ from countries that primarily rely on administrative and ethical oversight, which may increase legal risks for international scientific cooperation.

3.3 Exposed Issues

While the rapid development of gene-editing technology in China has promoted medical progress, it has also exposed numerous issues in legal and social governance. From the perspective of criminal regulation, current criminal law mainly addresses acts such as the illegal collection of human genetic resources and the unlawful implantation of gene-edited embryos. However, with the continuous emergence of new technologies like CRISPR, existing legal provisions have lagged, making certain behaviors difficult to clearly define (25). At the same time, ethical review exerts limited binding force in scientific research, and the connection between law and ethics is insufficient, with reliance on criminal penalties potentially inhibiting scientific innovation. Moreover, relevant regulations are dispersed across various laws and administrative documents, supervisory responsibilities overlap, coordination is inadequate, and alignment with international standards remains insufficient. At the public level, although some groups have a basic understanding of gene-editing technology, awareness of specific events remains low, particularly among individuals with lower educational attainment, reflecting uneven scientific literacy. Meanwhile, gene editing may lead to hidden discrimination and social fairness issues, and inadequate legal protection further heightens public concern over potential risks. In summary, the development of gene-editing

² Table 1: Key Legislative and Regulatory Frameworks for Gene Editing Technology in China.

Table 1: Key Legislative and Regulatory Frameworks for Gene Editing Technology in China

Date	laws and regulations	Ministry
1993	Administrative Measures for the Safety of Genetic Engineering	Science and Technology Committee
1998	Interim Measures for the Administration of Human Genetic Resources	Ministry of Science and Technology & Ministry of Health
2003	Ethical Guidelines for Research on Human Embryonic Stem Cells	Ministry of Science and Technology & Ministry of Health
2015	Administrative Measures for Clinical Research on Stem Cells (Trial)	National Health and Family Planning Commission & State Food and Drug Administration
2016	Measures for Ethical Review of Biomedical Research Involving Human Subjects	National Health and Family Planning Commission
2020	Safety Management Measures for Biotechnology Research and Development	Ministry of Science and Technology
2021	Civil Code of the People's Republic of China	National People's Congress
2021	Measures for Ethical Review of Life Sciences and Medical Research Involving Humans (Draft for Comment)	National Health Commission

technology exposes problems such as lagging legislation, weakened ethical constraints, fragmented regulation, and insufficient public awareness, necessitating responses through systematic legislation, strengthened ethics and public education, improved regulatory systems, and closer alignment with international standards.

4. Future Pathways for Improvement of Gene Editing Technology

4.1 Strengthening Public Participation

In the governance of gene editing technology, strengthening public participation is an essential approach to alleviating ethical controversies. At present, China's regulation of gene editing mainly relies on experts and administrative authorities, while the public often remains absent, resulting in insufficient social trust and information asymmetry. It is necessary to establish multi-level platforms for public communication, enabling diverse groups to express opinions in policymaking, ethical review of research, and risk assessment.

For example, public representatives could be introduced into the ethical review process of major scientific projects, or public awareness could be enhanced through science popularization and open hearings to ensure the right to know and participate. Public participation not only increases the transparency and legitimacy of decision-making but also helps achieve risk-sharing and balance of interests in a value-pluralistic society, thereby promoting the sustainable development of gene editing (26).

4.2 Improving the Legal and Regulatory Framework

Improving the legal and regulatory framework is a fundamental step to addressing ethical controversies. Although China has already amended the Criminal Law, introduced administrative regulations, and issued ethical guidelines to regulate illegal human gene editing activities, problems remain, including vague legal provisions, fragmented regulatory standards, and insufficient

enforcement (27). It is necessary to further refine legislation by clearly defining the boundaries of gene editing research and applications, particularly by setting strict prohibitions in areas involving human germ cells and embryos (28). At the same time, a coordinated regulatory mechanism should be established to ensure information sharing and joint enforcement among science, health, and judicial authorities, thereby enhancing regulatory effectiveness. By strengthening the legal framework and improving institutional enforcement, it is possible to safeguard scientific innovation while effectively preventing ethical and social risks.

4.3 Promoting Ethical Education and Scientific Self-Regulation

Promoting ethical education and scientific self-regulation is another important approach to addressing the ethical controversies surrounding gene editing. At present, some researchers, in their pursuit of academic breakthroughs and international competitiveness, tend to overlook a comprehensive assessment of ethical risks. To address this, bioethics education should be strengthened within the training system for researchers, making ethical competence an integral part of scientific capability. At the same time, research institutions should establish robust self-regulatory mechanisms, including internal rules, academic norms, and disciplinary measures, to create a system of clear responsibilities and effective accountability (29). The scientific community should also foster an academic culture that regards ethics as a fundamental bottom line, promoting both self-supervision and peer oversight to cultivate moral consciousness beyond institutional constraints. Only by emphasizing both ethical education and scientific self-regulation can scientific progress be advanced while avoiding the recurrence of ethical misconduct.

4.4 Promoting International Cooperation and Aligning with Global Standards

Promoting international cooperation and aligning with global standards is a necessary pathway for enhancing the governance of gene editing (30). Gene editing technology is highly transnational and shared, and relying solely on the regu-

lation of a single country is insufficient to comprehensively address potential ethical and safety risks. Therefore, China should actively participate in the development of international ethical guidelines and technical standards, fostering global consensus and coordinated mechanisms. At the same time, cross-border scientific collaborations require strengthened compliance review and risk assessment to prevent the emergence of “ethical loopholes,” where research circumvents ethical constraints due to regulatory differences. Aligning with international norms can not only enhance the legitimacy and credibility of domestic research but also promote innovation steadily in global scientific competition while upholding ethical standards and social responsibility.

5. Conclusion

Gene editing technologies, exemplified by CRISPR-Cas9, offer transformative scientific potential while simultaneously presenting profound legal and ethical challenges. The 2018 “gene-edited babies” incident in China exposed serious deficiencies in regulatory oversight, ethical governance, and public participation, highlighting the urgent need for a multidimensional governance framework. Such a framework should integrate robust legal regulation, transparent ethical review mechanisms, active public engagement, professional self-discipline within the scientific community, and strengthened international cooperation. Through this comprehensive approach, China can balance innovation with accountability, prevent unethical experimentation, and promote the responsible and sustainable development of gene editing technology. Future research should further explore public attitudes through empirical methods, assess comparative governance experiences across jurisdictions, and develop mechanisms to enhance compliance and ethical awareness, thereby contributing to the establishment of a more coherent, evidence-based, and globally harmonized governance system for emerging biotechnologies.

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EXPLORING THE ETHICAL BEHAVIOUR OF YOUTH ENGAGEMENT IN DIGITAL FINANCE: RISK PERCEPTIONS AND SECURITY VULNERABILITIES IN BIG DATA-DRIVEN SUPPLY CHAIN PLATFORMS

Tang Tao¹, Ma Yu Jie²

Abstract: The rapid proliferation of digital finance in emerging economies has prompted new inquiries into the ethical, strategic, and technological orientations of youth-led enterprises. This study investigates how fintech startups founded by young entrepreneurs in BRICS nations (Brazil, Russia, India, China, and South Africa) frame their organizational intent through mission and vision statements. Drawing upon a thematic analysis of 25 companies, the research examines the articulation of six critical constructs: ethical behavior, youth engagement, digital finance, risk perception, security vulnerabilities, and big data-driven supply chain platforms. The findings reveal a dominant emphasis on digital innovation and ethical positioning, with digital finance (34.7%) and ethical behavior (32.6%) emerging as the most frequently addressed themes. Conversely, risk-related narratives and cybersecurity discourse remain marginal, while youth engagement is conspicuously absent from most strategic texts, despite the demographic profile of the founders. Cross-national comparisons further underscore variation in thematic comprehensiveness, with Brazil and South Africa exhibiting the broadest strategic coverage. These results highlight both the potential and the narrative blind spots of youth-led digital finance enterprises in the Global South. The study advances theoretical discourse at the intersection of generational entrepreneurship, digital ethics, and platform governance, and offers actionable implications for regulators, investors, and founders aiming to foster resilient, inclusive, and ethically grounded fintech ecosystems.

Keywords: youth-led entrepreneurship, digital finance, ethical behavior, fintech in emerging markets, thematic analysis (BRICS)

Exploración del comportamiento ético de la participación de los jóvenes en las finanzas digitales: percepciones de riesgo y vulnerabilidades de seguridad en las plataformas de la cadena de suministro basadas en *Big Data*

Resumen: La rápida proliferación de las finanzas digitales en las economías emergentes ha impulsado nuevas indagaciones sobre las orientaciones éticas, estratégicas y tecnológicas de las empresas lideradas por jóvenes. Este estudio investiga cómo las startups fintech fundadas por jóvenes emprendedores en los países BRICS (Brasil, Rusia, India, China y Sudáfrica) definen su propósito organizacional a través de declaraciones de misión y visión. A partir de un análisis temático de 25 empresas, la investigación examina la articulación de seis constructos críticos: comportamiento ético, participación juvenil, finanzas digitales, percepción de riesgos, vulnerabilidades de seguridad y plataformas de cadenas de suministro basadas en big data. Los hallazgos revelan un énfasis dominante en la innovación digital y el posicionamiento ético, siendo las finanzas digitales (34,7%) y el comportamiento ético (32,6%) los temas más abordados. Por el contrario, las narrativas relacionadas con el riesgo y el discurso sobre ciberseguridad siguen siendo marginales, mientras que la participación de los jóvenes brilla por su ausencia en la mayoría de los textos estratégicos, a pesar del perfil demográfico de los fundadores. Las comparaciones transnacionales subrayan aún más la variación en la exhaustividad temática, siendo Brasil y Sudáfrica los que presentan la cobertura estratégica más amplia. Estos resultados resaltan tanto el potencial como los puntos ciegos narrativos de las empresas de finanzas digitales lideradas por jóvenes en el Sur Global. El estudio promueve el discurso teórico en la intersección del emprendimiento generacional, la ética digital y la gobernanza de plataformas, y ofrece implicaciones prácticas para reguladores, inversores y fundadores que buscan fomentar ecosistemas fintech resilientes, inclusivos y con fundamento ético.

Palabras clave: emprendimiento juvenil, finanzas digitales, comportamiento ético, fintech en mercados emergentes, análisis temático (BRICS)

Explorando o comportamento ético do envolvimento de jovens em finanças digitais: percepções de risco e vulnerabilidades de segurança em plataformas de cadeias de suprimento baseadas em megadados (*big data*)

Resumo: A rápida proliferação de finanças digitais em economia emergentes suscitou novas investigações sobre as orientações éticas, estratégicas e tecnológicas de empresas lideradas por jovens. Esse estudo investiga como startups de fintech criadas por jovens empreendedores em nações do BRICS (Brasil, Rússia, Índia, China e África do Sul) definem sua intenção organizacional por

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meio de declarações de sua missão e visão. Com base em uma análise temática de 25 empresas, a pesquisa examina a articulação de seis constructos críticos: comportamento ético, envolvimento de jovens, finança digital, percepção de risco, vulnerabilidades de segurança e plataforma de cadeias de suprimento baseadas em megadados (big data). Os achados revelam uma ênfase dominante em inovação digital e posicionamento ético com finança digital (34,7%) e comportamento ético (32,6%) emergindo como temas mais frequentemente contemplados. Em contrapartida, narrativas relacionadas a risco e discurso sobre segurança cibernética permanecem marginais, enquanto envolvimento de jovens está manifestamente ausente da maioria dos textos estratégicos, a despeito do perfil demográfico dos fundadores. Comparações transnacionais reforçam ainda mais a variação em abrangência temática, com o Brasil e a África do Sul exibindo a cobertura estratégica mais abrangente. Esses resultados ressaltam tanto o potencial quanto os pontos cegos da narrativa de empreendimentos de finança digital liderados por jovens no Sul Global. O estudo contribui para o discurso teórico na intersecção do empreendedorismo intergeracional, ética digital e governança de plataforma, oferecendo soluções práticas para reguladores, investidores e fundadores que buscam fomentar ecossistemas de fintech resilientes, inclusivos e eticamente baseados.

Palavras chave: empreendedorismo liderado por jovens, finança digital, comportamento ético, fintech em mercados emergentes, análise temática (BRICS)

Introduction

The rapid expansion of digital finance in emerging economies has significantly transformed the financial inclusion framework, particularly within the BRICS nations—Brazil, Russia, India, China, and South Africa. These countries, characterized by vibrant youth demographics and swiftly digitizing economies, are progressively depending on novel financial technology to address conventional disparities in economic engagement. Youth-led digital finance firms have arisen as drivers and indicators of extensive socio-technological transformations. Nonetheless, their involvement is fraught with ethical, operational, and structural issues, especially at the intersection of digital finance, big data, and supply chain infrastructures(1).

The digital banking landscape necessitates examining the interplay between ethical conduct, adolescent involvement, and risk perception. Young entrepreneurs are responding to technological advancements and actively influencing the ethos and architecture of financial services in their nations. Their participation in founding organizations that adopt ethical frameworks and manage the intricacies of risk, data security, and transparency is particularly crucial in evolving regulatory landscapes where these considerations remain underdeveloped. As digital ecosystems proliferate, concerns regarding security risks and data governance are increasingly integrated into the strategy frameworks of these youth-led firms(2,3).

This study adopts an innovative methodology by analyzing the vision and mission statements of digital finance enterprises established by young entrepreneurs in BRICS nations. This study employs a comparative thematic analysis of key strategic papers to reveal how young founders express ethical ideals, tackle risk and security issues, and conceptualize youth involvement in data-driven financial contexts. These vision and mission statements function as declarations of organizational intent and as culturally and contextually integrated texts that disclose underlying objectives, assumptions, and socio-technological commitments(4,5).

This inquiry emphasizes big data-driven supply chain platforms, recognizing the growing convergence of financial services and digital logistics systems across BRICS economies. This interconnection is essential for comprehending how emerging digital finance firms recognize and address operational weaknesses and ethical obligations in high-volume, data-intensive contexts. The study examines whether these firms regard adolescent participation as a strategic and ethical necessity in digital transformation rather than a demographic issue(6,7).

This research analyses 25 companies—five from each BRICS nation—to create a cross-national thematic map of values, narratives, and strategic priorities inherent in youth-led fintech entrepreneurship. The objective is to discern convergent and divergent patterns in integrating ethical behavior, digital finance inclusion, risk awareness, and data security consciousness within the foundational visions of these companies. This investigation enhances comprehension of youth agencies in digital economies and facilitates more refined policymaking and governance frameworks that address the ethical aspects of fintech development in emerging regions(8,9).

Literature review

Overview of Digital Finance in BRICS Economies

The digital financial scene in BRICS nations has developed due to technical progress, legislative liberalization, and socio-economic demands. Each BRICS nation demonstrates unique paths in fintech advancement—China and India excel in payment infrastructure and financial inclusion, Brazil pioneers open banking frameworks, Russia promotes cryptocurrency adoption despite regulatory challenges, and South Africa integrates formal and informal finance via mobile technologies(10). Nonetheless, despite common goals of financial democratization, these economies encounter inherent inequalities in digital infrastructure, regulatory sophistication, and overall digital literacy among the people. The variability in digital finance adoption highlights the necessity to contextualize technical dissemination within national institutional frameworks and state-market interactions(11).

While digital finance is frequently lauded for enhancing accessibility and efficiency, it simultaneously exacerbates pre-existing power and data governance disparities. The regulation of digital financial services is inconsistent among BRICS nations, exhibiting disparities in enforcing consumer protection, data privacy, and cybersecurity standards. Furthermore, the swift expansion of fintech has, in certain cases, surpassed the capabilities of financial regulators, leading to disjointed oversight and regulatory gaps. These characteristics undermine the presumption that digital money within BRICS is intrinsically inclusive or stable. A comprehensive examination is necessary—one that combines macro-level development frameworks with micro-level user experiences and socio-cultural adaptations of digital financial instruments(12,13).

Youth Entrepreneurship in Fintech Ecosystems

Youth entrepreneurship in fintech embodies a dynamic of disruption and democratization in emerging economies. Within BRICS, emerging entrepreneurs are utilizing mobile-first frameworks and blockchain technology to combat financial disadvantages while simultaneously transforming the cultural narrative of entrepreneurship from an elite legacy to one grounded in digital-native adaptability. Government initiatives, including start-up incubators, fintech sandboxes, and digital innovation grants, have fostered youth-led enterprises; however, the degree of youth integration into fintech ecosystems is contingent upon educational access, capital availability, and regional innovation hubs. Youth entrepreneurship often thrives despite structural limitations, propelled by necessity as much as opportunity(14-16).

However, the joyful narrative around youth-led fintech frequently neglects structural obstacles and ethical oversights. Inadequate governance experience, immature risk management protocols, and a lack of awareness about socio-cultural ethics may render youth-led enterprises susceptible to mission drift, technology overextension, and the misuse of user data. Furthermore, the fetishization of “disruption” may diminish the significance of the long-term sustainability and social responsibility of these firms. Consequently,

the analysis of youth entrepreneurship in fintech should extend beyond innovation measurements to encompass ethical frameworks, intergenerational power dynamics, and the socio-political integration of youth into digital financial ecosystems(17).

Ethical Behavior in Digital Financial Services

Ethical considerations in digital financial services encompass justice, openness, responsibility, and trust. Numerous digital finance transactions’ intangible and automated characteristics have challenged conventional understandings of ethical behavior in service provision. In BRICS nations, where initiatives for financial inclusion frequently engage marginalized and digitally disadvantaged groups, the consequences of ethical failures are especially significant(18). Concerns like algorithmic bias, unethical micro-lending, opaque fee structures, and predatory surveillance tactics undermine the ethical integrity of new financial platforms. Moreover, unethical practices may continue to thrive, masquerading as innovation and convenience in settings devoid of stringent consumer data protection legislation or financial literacy(19,20).

Ethics in digital finance is fundamentally a strategic and cultural attitude integrated into the organizational architecture rather than solely a compliance issue. Numerous fintech companies, especially startups, lack established ethical frameworks or formal accountability systems, instead depending on swift experimentation and market-driven adjustments. This may result in a disconnect between technological proficiency and ethical accountability(21). As digital financial ecosystems become more integrated with supply chains, health systems, and identity infrastructures, ethical violations pose a risk of systemic consequences. Consequently, examining ethical conduct in digital finance must scrutinize organizational aims and infrastructural ramifications, especially in youth-led enterprises where growth demands may eclipse ethical foresight(22).

Youth Engagement, Risk, and Systemic Challenges in Digital Finance and Supply Chain Integration

Engagement and agency of youth in technological innovation are crucial in influencing the digital finance sector within BRICS nations, as young entrepreneurs serve as both users and creators of financial innovations. Their involvement signifies a generational transition towards nimble, mobile-centric solutions that rectify deficiencies in financial inclusion. This engagement transpires within intricate risk landscapes where perceptions of digital finance risks—such as fraud, volatility, and privacy breaches—are frequently influenced by inadequate financial literacy and emerging regulatory control(23). These risk perceptions affect adoption behaviors and design decisions in youth-led platforms, leading to underestimating systemic vulnerabilities or overcompensation through excessively cautious architectures. Concurrently, the dependence on big data engenders significant security concerns, particularly in startups where cybersecurity resources may be inadequate and ethical foresight is weak. Integrating financial services with digital supply chain platforms heightens concerns around data quality, algorithmic fairness, and platform governance due to the convergence of logistical and transactional data. These dynamics underscore the importance of critically examining how youth-led digital finance initiatives in BRICS navigate innovation, risk, and responsibility in technologically complex and institutionally diverse ecosystems(24).

Vision and Mission Statements and Thematic Analysis in Strategic Communication

Vision and mission statements embody an organization's fundamental identity, long-term goals, and ethical principles. Within youth-led digital finance enterprises, particularly in BRICS countries, these statements serve as marketing instruments and narrative structures that elucidate how young founders perceive their influence in constructing socio-technical futures. Vision statements generally express aspirational objectives and future-focused principles, whereas mission statements highlight present operational strategies and obligations to stakeholders(25). Together, they embody the founders' ingrained views regarding ethics, innovation, youth involvement, risk accountability, and their expected impact on financial ecosystems. Examining these documents offers an essential understanding of the discursive

formation of youth entrepreneurship and the articulation of ethical principles and digital priorities to internal and external stakeholders(26).

The thematic analysis provides a rigorous qualitative approach for methodically deriving meaning from strategic texts in strategic communication research. This method allows researchers to discern, examine, and elucidate patterns of significance—termed themes—within textual data. Thematic analysis reveals overt commitments and underlying discourses that influence the direction of an organization's vision and mission statements. It is especially beneficial in comparative cross-national research since it facilitates the discovery of culturally and contextually specific narratives while simultaneously uncovering broader similarities across cases. This study utilizes thematic analysis to identify recurring constructs such as ethical behavior, youth empowerment, digital inclusivity, risk awareness, and security consciousness—elements that delineate organizational priorities and reflect the socio-political and technological environments of BRICS nations(27,28).

Cross-National Perspectives on Fintech Ethics and Governance

The ethics and governance of fintech vary significantly among countries, shaped by varying regulatory capabilities, cultural standards, and degrees of technology advancement. The variation across BRICS countries is particularly evident, as each government implements unique policy frameworks, compliance standards, and institutional responses to the swift expansion of digital banking. China's paradigm prioritizes state-driven governance and data sovereignty, whereas Brazil embraces open banking initiatives bolstered by progressive regulatory frameworks(29). Geopolitical limitations and fragmented cryptocurrency initiatives hinder Russia's strategy, while India advances financial inclusion via Aadhaar-integrated digital identification frameworks. Although smaller, South Africa's fintech sector is characterized by hybrid governance structures integrating informal financial practices with formal digital innovations. Diverse methodologies influence the comprehension and implementation of ethical issues across international boundaries, such as data privacy, algorithmic responsibility, and

user protection. A cross-national view provides a crucial framework for comprehending that ethics in fintech are not universal but contested within distinct political, economic, and cultural contexts(30,31).

Nonetheless, these national disparities result in a fragmented global framework where fintech governance is applied inconsistently, especially concerning youth participation, systemic risk, and technology accountability. Fintech businesses founded by youth frequently function in ambiguous legal environments where legislative progress fails to keep pace with technological innovation. Some jurisdictions provide regulatory sandboxes and incentives for youth, while others lack institutional backing for ethical entrepreneurship, heightening the danger of governance failures. A comparative cross-national approach elucidates best practices and regulatory advances while revealing normative tensions between innovation and control, inclusiveness and surveillance, profit and accountability. This approach is crucial for comprehending how BRICS nations may jointly establish ethical norms adaptable to local contexts while maintaining sufficient rigor to guarantee systemic integrity in digital finance(32,33).

Gaps in Literature: Interlinking Ethics, Youth, and Supply Chain Finance

Notwithstanding the expanding corpus of research on fintech innovation, digital inclusion, and ethical governance, a significant gap persists in the literature regarding the nexus of youth entrepreneurship, ethical conduct, and digital supply chain finance—especially in emerging markets such as the BRICS nations. Current research frequently addresses these domains in isolation: youth engagement is typically analyzed through startup ecosystems or digital adoption metrics; ethical behavior is considered in abstract or compliance-focused contexts; and supply chain finance is predominantly investigated from operational or institutional viewpoints. This compartmentalization neglects the interrelated manner in which young fintech founders are shaping—and being shaped by—the developing ethics of financial-technological integration in supply chain environments. The scant research addressing these intersections predominantly concentrates on

Global North economies or major multinational firms, neglecting youth-driven innovation in the Global South(34). This study focuses on young agencies as a key driver of ethical innovation in digital supply chain finance. This research examines how young entrepreneurs in BRICS nations express their ethical convictions in strategic texts, particularly vision and mission statements, thereby uncovering the evolving values, goals, and risk sensitivities influencing the future generation of fintech infrastructures(35,36).

Methodology

Research Methodology

This study employs a qualitative, exploratory, and cross-national comparative framework to examine how youth-led digital finance enterprises in BRICS nations articulate ethical conduct, risk awareness, and strategic orientations in their vision and mission statements(37,38). The research operates within an interpretive framework, focusing on deriving meaning from strategic textual narratives instead of quantifying performance metrics. The selection of vision and mission statements as the unit of analysis is based on their role as authoritative documents that articulate organizational principles, stakeholder commitments, and strategic identity(39-41).

Sampling Methodology

A purposive sample method was utilized to discover youth-founded digital finance enterprises in the five BRICS nations—Brazil, Russia, India, China, and South Africa. Five companies were chosen from each country (total n=25) according to the following criteria: (1) established or co-established by an individual aged 35 or younger at the time of the company's inception; (2) currently functioning within the digital finance sector, encompassing, but not limited to, digital payments, lending platforms, cryptocurrency finance, or supply chain financing; (3) possessing publicly available and official vision and mission statements disseminated through websites, investor reports, or policy documents. This sampling guaranteed geographic, cultural, and technological diversity within the digital financial ecosystem while preserving theme coherence(42).

Data Acquisition

Data were gathered from official corporate websites, annual reports, white papers, and authenticated third-party fintech directories from May to July 2025. Each company's vision and purpose statements were obtained in their original format. Certified translations were procured for statements unavailable in English to verify semantic accuracy. Secondary data, including founder profiles, launch dates, and platform types, were collected to enhance contextual understanding but were not analyzed thematically in the primary analysis.

Analytical Procedure

The research utilized thematic analysis as its primary analytical approach, adhering to Braun and Clarke's six-step framework: familiarisation, initial coding, theme development, theme review, theme definition, and report generation. Vision and mission statements were input into qualitative analysis software (e.g., NVivo) to enable inductive and deductive coding. A hybrid coding approach was employed: inductive codes arose organically from the data, whereas deductive codes were guided by the study's theoretical framework—specifically, the keywords contained in the research title: ethical behavior, youth engagement, digital finance, risk perceptions, security vulnerabilities, and big data-driven supply chain platforms. This method facilitated the identification of emergent themes and the validation of concepts(42).

Cross-National Comparative Framework

The thematic outcomes were compared within and within BRICS nations to guarantee analytical rigor across national examples. Thematic patterns were analyzed considering institutional, regulatory, and socio-economic contexts, facilitating the interpretation of common and differing strategic aims. Patterns were analyzed for thematic density, recurrence, and conceptual overlaps to discern macro-level trends and micro-level variations. A comparison matrix was created to visually represent the significance of the theme by country and evaluate how national settings influence ethical, technological, and risk-related discourses in

youth-led fintech ventures(43).

Reliability and Authenticity

To guarantee credibility, transferability, and confirmability, the study utilized methodological triangulation by validating vision and mission statements with publically accessible interviews and investor briefings, when applicable. Peer debriefing sessions and inter-coder agreement assessments confirmed the consistency of coding. Reflexivity was upheld during the analytical process to oversee researcher bias, especially in understanding ethical intent from business discourse(38).

Data Analysis

Brazilian Companies

Table 1 Brazilian Youth-Led Digital Companies

S No.	Theme	Frequency	Percentage
1	Ethical Behavior	5	100%
2	Youth Engagement	0	0%
3	Digital Finance	5	100%
4	Risk Perception	1	20%
5	Security Vulnerabilities	1	20%
6	Big Data-Driven Supply Chain Platforms	1	20%

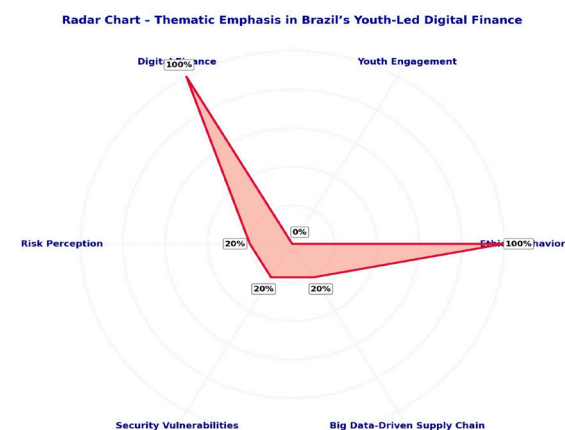


Figure 1 Brazilian Youth-Led Digital Companies.

Table 1 and Figure 1 show the thematic analysis of five youth-founded Brazilian digital finance companies reveals a strong and consistent empha-

sis on ethical behavior and digital finance, with both themes appearing in 100% of the vision and mission statements. These companies frequently employ terms such as “empower,” “inclusive,” “transparent,” and “accessible,” signaling a shared strategic commitment to ethical values in the delivery of financial services. This linguistic framing positions them not just as technological ventures but as ethically responsible institutions aiming to democratize financial access. Likewise, the universal presence of digital finance-related terminology reflects the core nature of their business models—ranging from neobanking to mobile wallets and automation—highlighting the extent to which digital transformation is embedded in their operational and value narratives.

In contrast, other thematic areas receive significantly less attention. Notably, youth engagement is absent from all five companies’ strategic statements, even though each organization was founded by individuals under the age of 30.6. This absence suggests a disconnect between the age of the founders and the demographic framing of their platforms. Rather than emphasizing generational leadership or youth empowerment in finance, the statements adopt a broader, more universal consumer focus. Similarly, risk perception and security vulnerabilities each appear in only one company’s statements, indicating a low frequency of concern—at least in rhetorical terms—for cybersecurity, data protection, or user risk awareness. This underrepresentation is particularly surprising given the financial sector’s inherent exposure to digital threats and user trust concerns.

A minimal presence was also found for references to big data-driven supply chain platforms. Only one company, Asaas, touched on concepts related to process automation and efficiency—indirectly referencing backend technological infrastructure. This suggests that while data and automation may be core to operations, they are not being prominently communicated as strategic themes. Demographically, the founders of these firms average approximately 30.6 years of age, solidly within the youth entrepreneurship bracket. However, the fact that youth engagement is not explicitly highlighted implies a deliberate choice to separate personal identity from public branding.

Russian Companies

Table 2 Russian Youth-Led Digital Companies

S No.	Theme	Frequency	Percentage
1	Ethical Behavior	3	60
2	Youth Engagement	0	0
3	Digital Finance	1	20
4	Risk Perception	1	20
5	Security Vulnerabilities	0	0
6	Big Data-Driven Supply Chain Platforms	3	60

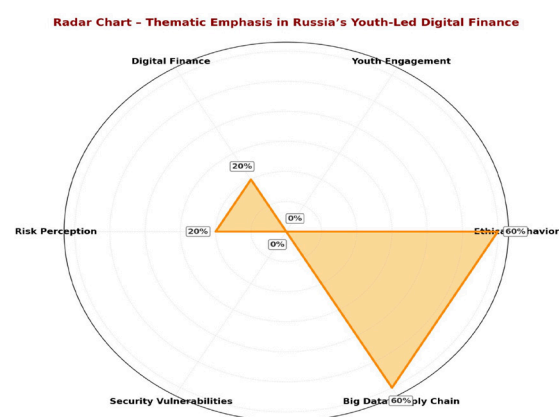


Figure 2 Russian Youth-Led Digital Companies

Table 2 and Figure 2 show the thematic analysis of vision and mission statements from five youth-founded Russian digital finance companies present a nuanced picture of how these firms frame their strategic and ethical priorities. Ethical behavior emerges as a prominent theme, present in 60% of the companies. This suggests that a majority of the selected companies position themselves as purpose-driven or socially responsive, using terms like “accessible,” “democratize,” or “transform” to communicate a value-oriented mission. However, unlike Brazilian companies—where ethical language was universal—this figure indicates a less consistent emphasis on ethical positioning in the Russian digital finance narrative.

Interestingly, the theme of **youth engagement** is again absent, despite the relatively young average founder age of **33.2 years**. This may indicate that Russian founders, much like their Brazilian counterparts, do not consider age or generational identity to be a strategic differentiator in their

public communications. Their messaging remains focused on product functionality and technological disruption rather than demographic or generational branding.

The **digital finance** theme, which was expected to dominate given the nature of the sector, appears in only 20% of the companies. This is surprisingly low and suggests that while these firms operate within or adjacent to fintech, many describe themselves more broadly as platforms, tech innovators, or infrastructure providers. For example, companies like Samokat and Planeta.ru lean more toward logistics or crowdfunding ecosystems, and their strategic language reflects that broader scope.

Risk perception appears in just one company, accounting for 20% of the sample, highlighting a limited engagement with themes related to safety, protection, or risk management. In a digital context where trust and cybersecurity are foundational, this absence raises questions about how risk-related assurances are communicated—if at all—within startup narratives. Compounding this is the complete absence (0%) of language associated with **security vulnerabilities**, such as data protection or privacy, which is particularly notable for companies involved in investment, payments, or user data-driven services.

A standout feature in the Russian data is the unexpectedly high occurrence of the theme **Big Data-Driven Supply Chain Platforms**, found in 60% of the companies. This suggests that several Russian startups view themselves as technology infrastructure providers or enablers of process and platform-based efficiencies. The frequent use of terms like “platform,” “efficiency,” and “process” underscores their commitment to backend innovation and system-wide integration, even when it’s not explicitly branded as “big data” in the traditional sense. This differentiates the Russian fintech narrative from Brazil’s, where this theme was marginal.

Indian Companies

Table 3 Indian Youth-Led Digital Companies

S No.	Theme	Frequency	Percentage
1	Ethical Behavior	4	80
2	Youth Engagement	1	20
3	Digital Finance	4	80
4	Risk Perception	0	0
5	Security Vulnerabilities	0	0
6	Big Data-Driven Supply Chain Platforms	0	0

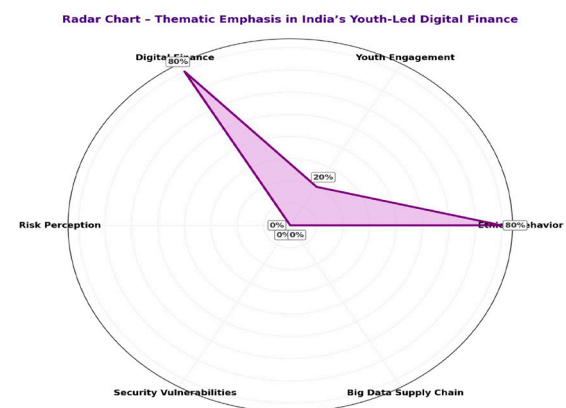


Figure 3 Indian Youth-Led Digital Companies

Table 3 and Figure 3 highlight that Indian youth-led digital finance firms strongly emphasize *ethical behavior* and *digital finance*, each present in 80% of cases. These companies frequently reference inclusivity, transparency, and access, reflecting a clear commitment to socially responsible innovation. Their operational language centers on digital tools such as credit platforms and online financial services, showcasing a digitally native business orientation. However, *youth engagement* appears in only one firm (20%), indicating limited alignment between the founders’ generational identity and their public messaging. This suggests a missed opportunity to brand themselves as generational change-makers, despite often targeting younger users. More critically, none of the companies reference *risk perception*, *security vulnerabilities*, or *big data supply chain platforms*. This omission may signal a strategic blind spot, particularly concerning user trust and platform security—vital in a context like India, where data privacy and fintech regulation are high-stakes

concerns. With an average founder age of 30.6 years, Indian fintechs meet the youth-led criterion but fall short in incorporating youth identity, platform risks, or data ethics into their strategic narratives. While their ethical and digital foundations are strong, stronger messaging on security, risk, and generational engagement could enhance differentiation and trust.

China

Table 4 Chinese Youth-Led Digital Companies

S No.	Theme	Frequency	Percentage
1	Ethical Behavior	1	20
2	Youth Engagement	0	0
3	Digital Finance	2	40
4	Risk Perception	0	0
5	Security Vulnerabilities	0	0
6	Big Data-Driven Supply Chain Platforms	2	40

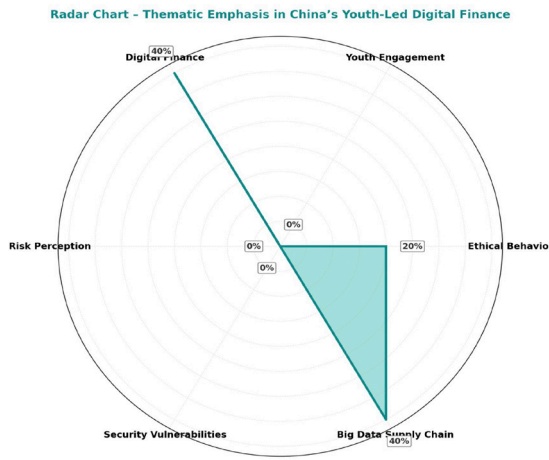


Figure 4 Chinese Youth-Led Digital Companies

South African youth-led digital finance firms in Table 4 and Figure 4 show strong emphasis on *digital finance* (80%) and moderate attention to *risk* and *security* (40%), reflecting a growing focus on platform reliability and inclusion. *Ethical behavior* is present but limited (40%), while *youth engagement* is entirely absent despite an average founder age of 31.6. This suggests a preference for institutional credibility over generational identity, pointing to an opportunity for more youth-reflective communication.

South Africa

Table 5 South African Youth-Led Digital Companies

S No.	Theme	Frequency	Percentage
1	Ethical Behavior	2	40
2	Youth Engagement	0	0
3	Digital Finance	4	80
4	Risk Perception	2	40
5	Security Vulnerabilities	2	40
6	Big Data-Driven Supply Chain Platforms	1	20

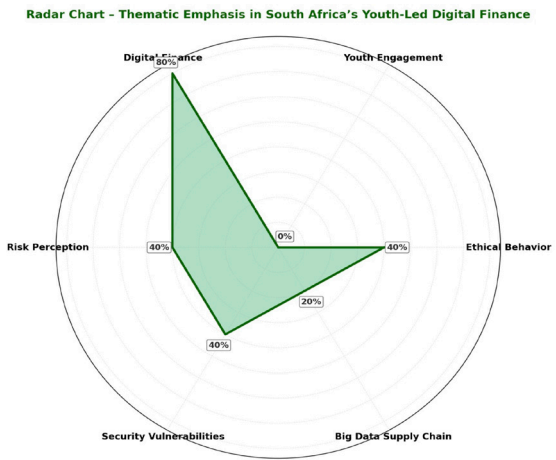


Figure 5 South African Youth-Led Digital Companies

Table 5 and Figure 5 highlight that South African youth-led digital finance firms strongly prioritize *digital finance* (80%), with firms like Yoco and TymeBank emphasizing innovation, inclusion, and payment accessibility. *Ethical behavior* appears in 40% of companies, reflecting partial commitment to values like affordability and empowerment. Notably, South Africa leads BRICS peers in *risk perception* and *security* discourse (40%), with firms explicitly referencing secure data practices and system reliability—suggesting a more mature fintech narrative. Despite founders averaging 31.6 years, *youth engagement* is entirely absent from public messaging, mirroring patterns across other BRICS nations. This signals a strategic preference for institutional credibility over generational identity, leaving a potential gap in youth-centered branding and inclusion.

Table 6 Country vs Thematic words highlighted BRICS

Theme	Brazil	Russia	India	China	South Africa	Total	Total (%)
Big Data-Driven Supply Chain Platforms	1	3	0	2	1	7	15.2
Digital Finance	5	1	4	2	4	16	34.7
Ethical Behavior	5	3	4	1	2	15	32.6
Risk Perception	1	1	0	0	2	4	8.6
Security Vulnerabilities	1	0	0	0	2	3	6.5
Youth Engagement	0	0	1	0	0	1	2.1
Total	13	8	9	5	11	46	
Total (%)	28.3	17.4	19.6	10.9	23.9		100

Overall, country vs. thematic words highlighted BRICS

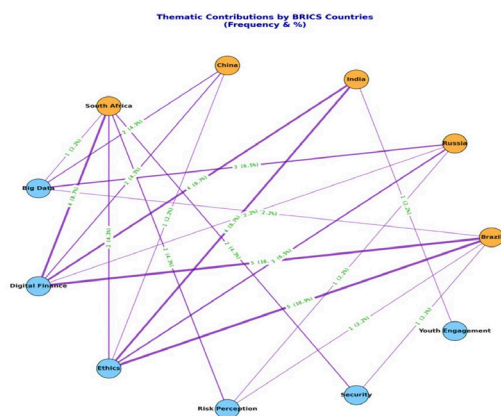


Figure 6 Country vs Thematic words highlighted BRICS

Table 6 and Figure 6 present the thematic focus of BRICS youth-led digital finance companies across six variables: *Ethical Behavior*, *Youth Engagement*, *Digital Finance*, *Risk Perception*, *Security Vulnerabilities*, and *Big Data-Driven Supply Chain Platforms*. *Digital Finance* (34.7%) and *Ethical Behavior* (32.6%) were the most emphasized themes, indicating a shared strategic orientation toward technological innovation and social inclusion. This aligns with the study's focus on ethical youth engagement in digital ecosystems. *Big Data Supply Chain* themes (15.2%) appeared mostly in Russia and China, highlighting a regional focus on platform infrastructure and backend optimization. In contrast, Brazil, India, and South Africa showed minimal emphasis in this area. *Risk Perception* (8.6%) and *Security Vulnerabilities* (6.5%) were underrepresented overall, with

South Africa being the only country addressing both to a meaningful degree. This raises concerns about narrative gaps in trust-building and digital resilience. *Youth Engagement*—central to the study—was nearly absent, appearing in only one Indian company (4%). This reflects a disconnect between founder identity and brand communication, suggesting a missed opportunity to highlight generational leadership. Cross-nationally, Brazil and South Africa exhibited the most comprehensive thematic profiles, each covering five out of six themes. China and Russia focused narrowly on digital and infrastructure-related topics, while India showed strength in ethical and digital framing but lacked security-related themes.

Discussions

This study examined how youth-led digital finance companies in BRICS countries strategically frame six key themes in their mission and vision statements: *Ethical Behavior*, *Youth Engagement*, *Digital Finance*, *Risk Perception*, *Security Vulnerabilities*, and *Big Data-Driven Supply Chain Platforms*. Analyzing 25 firms revealed both shared priorities and distinct regional narratives. Thematically, *Digital Finance* (34.7%) and *Ethical Behavior* (32.6%) dominated, highlighting a focus on inclusion, accessibility, and responsible innovation. Brazil and India emphasized ethical messaging, while Russia and China leaned toward infrastructural and data-driven positioning. *Big Data* themes (15.2%) were largely championed by Russia and China, whereas *Risk* (8.6%) and *Security* (6.5%) were widely under-addressed, with only South Africa showing moderate attention. A critical gap was *Youth Engagement*, mentioned by just one company, despite all founders

being under 35. This points to a broader trend: young fintech entrepreneurs favor institutional and technical legitimacy over generational identity. Brazil and South Africa exhibited the most balanced thematic coverage (83.3%), while China and India addressed only half the key themes. Visual mappings reinforced these asymmetries, emphasizing the role of national context in shaping strategic discourse.

Conclusion

This study analyzed how youth-led digital finance companies across BRICS nations frame their strategic focus through six core themes. Thematic analysis of 25 firms revealed strong emphasis on *digital finance* and *ethical behavior*, reflecting commitments to innovation and inclusion. However, significant gaps emerged—particularly the near-absence of *youth engagement*, and limited attention to *risk*, *security*, and *supply chain platforms*. Brazil and South Africa showed the broadest thematic coverage, while China and India were more narrowly focused. These findings highlight the need for more integrated, youth-conscious, and risk-aware narratives in shaping the future of fintech across emerging markets.

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A DESCRIPTION OF 'MORAL COMPETENCE' IN NURSING ACCORDING TO PATIENTS' AND NURSES' PERSPECTIVES: RESULTS FROM AN ITALIAN QUALITATIVE STUDY

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Abstract: There is a growing need for morally competent nurses to deal with increasingly complex situations and choices as encountered in professional daily life. However, there is no updated evidence about which characteristics, knowledge, skills, and attitudes a morally competent nurse should have and how to support their development. In the context of the EU-Erasmus+ funded project PROMOCON, this study aimed to describe the moral competences of nurses in Italy. A descriptive qualitative study was conducted, involving a purposeful sample of ten nurses and six patients' representatives in three focus groups. Findings were analyzed in an integrated manner using the content analysis. Nurses are morally competent when they provide personalised care, motivate the patients cared for, protect them in their choices, and set an example with their behaviour. They possess basic ethical, psychological, philosophical, humanistic and legal knowledge; they can understand and relate to others, not only patients/family members but also colleagues or students in difficulty by activating resources when necessary and being empathetic, patient, respectful, responsible, and flexible.

Keywords: nurses, moral competence, patient participation, focus groups, qualitative research

Descripción de la “competencia moral” en enfermería según la perspectiva de los pacientes y el personal de enfermería: resultados de un estudio cualitativo italiano

Resumen: Existe una creciente necesidad de enfermeras moralmente competentes para afrontar situaciones y decisiones cada vez más complejas, propias de la vida profesional diaria. Sin embargo, no existe evidencia actualizada sobre las características, conocimientos, habilidades y actitudes que debe poseer una enfermera moralmente competente ni sobre cómo apoyar su desarrollo. En el contexto del proyecto PROMOCON, financiado por la UE-Erasmus, este estudio tiene como objetivo describir las competencias morales de las enfermeras en Italia. Se realizó un estudio cualitativo descriptivo con una muestra específica de diez enfermeras y seis representantes de pacientes en tres grupos focales. Los hallazgos se analizaron de forma integrada mediante análisis de contenido, demostrando que las enfermeras son moralmente competentes cuando brindan atención personalizada, motivan a los pacientes que atienden, protegen sus decisiones y dan ejemplo con su comportamiento; poseen conocimientos éticos, psicológicos, filosóficos, humanísticos y legales básicos; pueden comprender y relacionarse con los demás, no solo con pacientes o familiares, sino también con colegas o estudiantes en dificultades, activando recursos cuando es necesario y siendo empáticas, pacientes, respetuosas, responsables y flexibles.

Palabras clave: enfermeras, competencia moral, participación de pacientes, grupos focales, investigación cualitativa

Uma descrição de “competência moral” em enfermagem de acordo com perspectivas de pacientes e enfermeira: resultados de um estudo qualitativo italiano

Resumo: Há uma crescente necessidade de enfermeiras moralmente competentes para lidar com situações e escolhas cada vez mais complexas como as encontradas na vida cotidiana profissional. Entretanto, não há evidência atualizada sobre quais características, conhecimentos, habilidades e atitudes, uma enfermeira moralmente competente deve ter e como apoiar seu desenvolvimento. No contexto do projeto PROMOCON, financiado pelo programa Erasmus da UE, esse estudo objetivou descrever as competências morais de enfermeiras na Itália. Um estudo descritivo qualitativo foi realizado, envolvendo uma amostra não probabilística de

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dez enfermeiras e seis representantes de pacientes em três grupos focais. Os achados foram analisados de uma forma integrada utilizando-se análise de conteúdo. Enfermeiras eram moralmente competentes quando elas forneciam cuidado personalizado, motivavam os pacientes cuidados, protegiam-nos em suas escolhas e davam um exemplo com seu comportamento. Elas possuíam conhecimentos básicos éticos, psicológicos, filosóficos, humanísticos e legais; elas podiam entender e relacionar-se com outros, não somente pacientes/membros da família como também colegas e estudantes em dificuldade, acionando recursos quando necessários, e sendo empáticas, pacientes, respeitosas, responsáveis e flexíveis.

Palavras chave: enfermeiras, competência moral, participação do paciente, grupos focais, pesquisa qualitativa

Introduction

Due to the challenges faced by healthcare systems all over the world, exacerbated by the pandemic, the staff shortage, and the change in patients' requirements, nurses and many other healthcare professionals are confronted with increasingly morally complex situations and choices(1). These challenges include delivering sub-optimal nursing care due to working in difficult environments with few nurses and internal (e.g., over different views on vaccination) or external (e.g., caring for sick people who are angry with the system) conflicts. Other challenges, which include, for example, the need to prioritize healthcare service access due to a lack of resources, are some of the issues that are calling for a reflection, also at the international level, upon the moral competences of nurses(2) and how to develop them(3).

Moral competence expresses the ability to recognise one's own emotions and values at stake that influence situations, reflect on them, and make a decision in the best interest of the person cared for(4). Moral competence is something that goes beyond ethical competence, which includes knowledge, skills, and abilities to handle specific ethical problems or dilemmas(5). The literature has long documented that morally competent nurses deliver care that is more attentive to people's needs, values, and principles(3,6). However, despite the efforts(7) devoted by nursing programs and professional mandates(8,9), also in line with the European directives that have just reaffirmed the need to train nurses on these aspects(10), there are still no guidelines on how to prepare nurses and how to support them(11). Furthermore, it is recommended that research approaches should go beyond the professional perspective, preventing the tendency to self-define the expected moral competences, in order to also consider that of the main stakeholders, i.e., patients receiving nursing care(8). Updating comprehension about the characteristics, knowledge, skills and attitudes that morally competent nurses should possess, as well as strategies to support their development, would help educators and professional bodies to advance lines of action.

To bridge this knowledge gap, a qualitative study was conducted to describe the moral competences

that nurses should possess on the basis of the views and perspectives of nurses and patient representatives.

Methods

Design

A descriptive qualitative study using focus groups to collect data(12) was conducted as part of European Erasmus funded project called PROMOCON (PROmoting a MORally COmpetent Nurse) (<https://promocon.upatras.gr/en/>). In the reporting phase, the guidelines Consolidated Criteria for Reporting Qualitative Research (COREQ) were followed(13).

Participants and Setting

Purposeful sampling was employed(14): three groups of a total of 16 participants were formed and the whole process (e.g., the interview analysis guide) followed a plan previously designed to assure the validity and reliability of the data.

In the first focus group, three volunteer nurses piloted the interview guide: they confirmed the comprehensibility of the questions without requesting any changes. In the second focus group, a group of practicing nurses from different care settings and who wished to participate were involved; support workers or professionals not in an active role were not eligible. Finally, in the third focus group, representatives of patient associations, who were either chairpersons or members and who wished to participate, were involved: those recruited by the health service (e.g., for outpatient treatments) or involved in the care of family members at the time of the study were not eligible. Sampling sought to ensure maximum heterogeneity of participants by ensuring five to nine participants per focus group(12).

Data Collection

All participants, who had had previous collaborations with the university and were known by researchers for their interest in ethical issues, were contacted by telephone: they were asked to participate after having been informed of the aims of the project and the method of data collection. Everyone signed up and filled in a demographic

data collection form. The focus groups were held in a room on the university campus in a quiet and confidential setting. A moderator (a nurse with a PhD who is an expert in qualitative research) led the group by asking questions

, and an observer (a nurse with a master’s degree, from a clinical setting) took some notes and observed non-verbal behaviours. Participants knew neither the moderator nor the observer. After the introductory phase, the guiding questions (Table 1) were asked.

The focus groups lasted approximately two hours each and were audio-recorded and transcribed verbatim. After three focus groups (one with patient representatives, two with nurses) the data appeared saturated(15) and the researchers decided to conclude the interviews. Repeated interviews to verify or better explore certain topics were not conducted; the transcripts and/or analyses of the focus groups were not returned to participants.

Table 1. Focus group questions

<i>Introductory warm-up and contextualisation questions</i>	
-	With respect to the concept of ‘moral competence of nurses’, what situations or experiences come to mind? This seems very positive (if the examples are positive) or negative (if the examples are negative). What other opposite experiences have you had?
-	Which morally ‘difficult’ situations involving nurses have you experienced or witnessed? Can you describe them?
<i>Specific questions consistent with the aims of the study</i>	
1.	What do you mean by ‘morally competent nurse’? How would you define a ‘morally competent nurse’? What are their main characteristics?
2.	In your opinion, what
-	knowledge
-	skills/competences
-	attitudes
	must nurses demonstrate in clinical practice in order to be considered ‘morally competent’?
3.	In your opinion, how should nurses be supported to develop their moral competence?
<i>Closing questions</i>	
-	Is there anything else you would like to share?

Data Analysis

Data analysis was conducted following a content analysis approach(16). After the transcription of the focus groups, two researchers jointly identified the most significant sentences. From these, the most important concepts representing them were highlighted. The coding process followed the three main research questions: (a) general characteristics of a morally competent nurse, (b) main components of nurses’ moral competence, and (c) tools or methods needed to support it. The data from the three focus groups (N, concerning nurses, R concerning patient representatives) were analysed manually by the researchers (see authors), first separately and then integrating them, highlighting similarities and differences.

The rigor of the study was assured through a set of three criteria for assessing qualitative research: credibility, transferability, and dependability. Credibility aims to demonstrate that the study was conducted in a way that ensured a rigorous description of the phenomenon under study. This was achieved by taking field notes and triangulation of data analysis through verification and discussion with all researchers. Transferability refers to the applicability of the findings to similar contexts or situations. This was accomplished by providing sufficient details and in-depth descriptions of participants’ experiences. Finally, dependability shows that the findings could be repeated. This was ensured with the help of outside reviewers, who supervised the entire process.

Ethical Considerations

The project was approved by the Institutional Review Board of the University of Udine, Italy (Ref No 33/2023). Participants were free to participate and could withdraw from the study at any time without repercussions. All results were anonymised so that participants and the examples they reported could not be identified.

Results

Characteristics of participants

Ten nurses and six representatives of patients’ associations were involved. The professional focus

Table 2. Focus groups: characteristics of participants

Nurses' focus group							
ID	Gender	Age	Qualification	Role	Experience (years)	Current setting	Current setting (years)
1	Female	26	Bachelor's Degree	Clinical nurse	3.5	Hospital	1.5
2	Male	38	Bachelor's Degree	Academic tutor	15	University ^a	1
3	Female	24	Bachelor's Degree	Clinical nurse	2.5	Hospital	2.5
4	Female	38	Master's Degree	Academic tutor	14	University	2
5	Male	48	Diploma	Nurse coordinator	23	Hospital	0.4
6	Male	23	Bachelor's Degree	Clinical nurse	0.4	Hospital	0.4
7	Female	47	Diploma	Nurse coordinator	23	Territory	7
8	Male	41	Master's Degree	Academic tutor	14	University	8
9	Female	28	Master's Degree	Clinical nurse	3.5	Hospital	3
10	Male	30	Bachelor's Degree	Clinical nurse	1	Territory	1
Patient protection associations' focus group							
ID	Gender	Age	Qualification	Association	Experience as		
					patient	caregiver	
1	Female	33	High School Diploma	Tribunale dei diritti dei malati (Patients rights tribunal)	No	No	
2	Female	38	University Degree	Associazione Italiana contro Leucemie, linfomi e mieloma (Italian Association against Leukemia, Lymphoma and Myeloma)	Yes	No	
3	Female	53	High School Diploma	Associazione Donatori di Midollo Osseo (Bone Marrow Donor Association)	No	Yes	
4	Female	65	High School Diploma	Associazione Nazionale Donne Operate al Seno (National Association of Breast Operated Women)	Yes	No	
5	Female	41	University Degree	Associazione Donatori di Midollo Osseo (Bone Marrow Donor Association)	Yes	Yes	
6	Female	39	University Degree	Tribunale dei diritti dei malati (Patients rights tribunal)	No	No	

^aLecturer in ethics

groups (Table 2) were composed of clinical nurses, academic tutors (of whom one was a lecturer in ethics) and ward managers with an average age of 34.3 years and a professional experience of approximately 10 years. Half were female and the majority possessed a nursing degree. The representatives of patients' associations were women, aged from 33 to 65 years, with a high school diploma or a university degree; some had lived experiences as patients and/or caregivers (Table 2) and represented associations with different aims.

The profile of a morally competent nurse

According to participants, morally competent nurses possess four visible characteristics that must be co-present:

They deliver personalised care: they can put the person at the centre, delving into their values, needs and situation; on such basis, they can offer 'tailored' care.

"So, in my opinion, morally competent nurses are nurses who can understand the situations they are in, to understand all the values at stake within that

particular situation and, let's say, understand what is best So, they're able to identify all the facets of the situation and grasp the values of the person and take them into account in the care to be provided." (N3)

"...tailor care to the patient's situation ... put the person at the centre by personalising care." (R4)

They motivate the person cared for, identifying the resources they can use to achieve the maximum degree of autonomy; they activate all possible strategies, encouraging patients to have confidence in their resources and to mobilise them.

"... they search where the resource is, pull it out to enable people in whatever setting they are, that is at home, in a hospital and on the territory, to be able to cope with what is happening to them. So, for me, competence and the ability to bring out the best of what's there, despite the moment." (N2)

"... they identify people's needs and understand what the patients' latent and residual resources are, to bring them to the maximum degree of autonomy in dealing with their illness." (R2)

They protect the people cared for and their right to make their own choices: even if at times these choices are not agreeable or understandable, morally competent nurses ensure full freedom of choice by supporting patients in their decisions.

"... be able to assist without judging and without 'influencing the patient's decisions' even if they are not in line with ... one's own convictions about the correctness of the situation one finds oneself in." (N2)

"I would include the ability to protect the person here." (R2)

They set an example with their behaviour both for the people cared for and their colleagues, especially the younger ones. In this way, they inspire other professionals, becoming a point of reference.

"And then excellence, in order to differentiate it from a standard competence, must necessarily be catalytic, i.e. nurses who are excellent on a moral level are nurses who drag others behind him/her, who also inspire colleagues and who also act as a reference for patients. And they do not necessa-

rily do this in their extra time as we were saying, of course, the pandemic situation has exacerbated the lack of time to devote to the care relationship, but probably ethically excellent nurses manage to make up for these moments precisely by optimising time." (N6)

"... let's say that the nurse is the closest link to the patient and therefore a point of reference..." (R6)

Knowledge, skills/behaviours, and attitudes of a morally competent nurse

Participants agree on the need for basic education, including philosophy, ethics, psychology, humanistic lessons – to understand the role of cultural differences in nursing practice – and legal aspects (e.g., Advance Healthcare Directives) (Table 3). Some skills were indicated by both focus groups, while others were indicated only by nurses. Both found morally competent a nurse who can (a) understand situations, needs and contexts: this means showing an understanding not only of what is going on, but also of the values involved, the responses of patients and family members/caregivers; (b) listen to and communicate not only with the sick person but also with the family, using appropriate and understandable words, establishing a close contact. To these, nurses also added the ability to (c) identify priorities, discuss issues with colleagues, and promote the activation of resources (e.g., ethics committees for clinical practice or peer ethics counseling) to delve into situations about which there is disagreement and for which broader discussion is needed; (d) support those who are in distress, whether they are students or colleagues.

Attitudes were instead described homogeneously by nurses and representatives of patients: the attitude for reflection and for asking oneself the right questions, to discover oneself and the others, to delve into situations, to know one's limits and to avoid errors generated by standard answers, was considered to be essential; the same applies to reflexivity, which makes nurses aware of their own needs for training or help when situations are very challenging or cannot be handled with the available knowledge and skills. Flexibility, which expresses the ability to adapt while keeping one's underlying principles intact, was also considered

Table 3. Knowledge, skills, and attitudes of a morally competent nurse

Knowledge	N	R	Quotes
<i>Philosophical, psychological, ethical</i>	x	x	“Definitely philosophy and ethical theories, both at the bachelor's and master's degree level, but especially at the bachelor's level because not everyone then continues their studies...” (N3) “Then in my opinion for them I would also do some philosophical practices.” (R5)
<i>Humanistic/cultural</i>	x	x	“...to understand the differences and have the basis for understanding.” (N2) “...to take into consideration behaviors or cultures different from our own because we will be dealing with diversity more and more.” (R3)
<i>Legal</i>	x	x	“...knowledge of the normative context within which we move because some situations require decisions that also have a normative framework e.g. Advance Healthcare Directives and the whole euthanasia discourse...” (N3) “If I have to think of the first thing that comes to mind, it's actually the normative framework.” (R5)
Skills	N	R	Quotes
<i>Interpreting situations and contexts</i>	x	x	“Maybe even knowledge of the context, in which I'm moving. Because in the end you know it by being in it. Like also the knowledge of the patient, going back to the example you were making: yes, cigarettes hurt but if I know that to him, in a context where I can allow to let it ring...” (N9) “...reflecting is something that allows you to interpret the situation and thus relate to the other and promote the enhancement of the individual person.” (R2)
<i>Listening</i>	X	x	“And listening to the caregiver or those close to the patient, to understand facets that the patient cannot express.” (N2) “Listening to each other.” (R3)
<i>Communicating</i>	x	x	“And I happened to, precisely, care for a pre-term infant with very experienced nurses from my department even if at times some resuscitations go wrong or we fail to, let's say, get the infant to survive, the way the communication to the family is then handled, the way the woman, the couple and let's say the family is actually cared for, now with covid they are able to get relatives in as well, in my opinion this is a great moral competence of my experienced colleagues.” (N3) “...because communication is fundamental at any time of life, in any sphere.” (R1)
<i>Identifying priorities</i>	X		“Contextualize the decision on priorities, for one patient one aspect is a greater priority than for others. So, in my opinion, this aspect is not the same for everyone, so it is prioritized for certain patients.” (N4)
<i>Discussing with/within the team</i>	X		“...a skill that all professionals will need to have. Discussions among peers, as well as within teams, to reflect upon what needs to be done or what could have been done or not.” (N4)
<i>Activating resources</i>	X		“Committees, rather than case discussions among various specialists, to understand the various possible solutions, in short, to be brought to the patient as well.” (N2)
<i>Supporting colleagues/students in distress</i>	X		“...always accompanying them and showing support to students and colleagues in particularly difficult situations.” (N3)
Attitudes	N	R	Quotes
<i>Asking oneself questions</i>	x	x	“...doubt, questions, placing oneself in a horizon not made of certainties, but actually of fluidity. The attitude is always based on

			discovering each other, on not taking anything for granted, on...having references maybe...even important ones, however always with a doubt..." (N7) "I see them as doubtful people, meaning that they ask themselves questions with respect to what they are doing or experiencing." (R3)
<i>Reflexivity</i>	x	x	"... it is necessary to reflect, to have a good deal of patience, ... to be calm and quiet in the situation in order to move forward..." (N2) "...I would add patience." (R2)
<i>Flexibility/adaptability</i>	x	x	"...sometimes it is necessary to change attitude and way of thinking as situations or opportunities change." (N5) "... adaptable while keeping their underlying principles... er... strong here, in short. References...not to get lost in that flexibility." (R4)
<i>Dedication</i>	x	x	"showing commitment to things, to issues ... devoting time to patients, but also to the team ..." (N7) "...an attitude toward the other..." (R4)
<i>Assuming responsibilities</i>	x	x	"...take responsibility for choices...take responsibility for the choice..." (N5) "...to know how to take charge of the person's problems, that is, to feel responsible, without stopping at mere performance or compartmentalization." (R4)

Legend: N, Nurse; R, Representative of patients' association.

Table 4. Tools or methods supporting nurses in the development of ethical knowledge, skills and attitudes

Tools/methods	N	R	Quotes
<i>Education</i>	x		"Because while you were asking the question the education came to my mind, starting from the basics first of all." (N7)
<i>Stimuli for ongoing reflection</i>	x		"... being helped to continually reflect ... an effort, a stimulus ... to wonder and think about what is happening ..." (N8)
<i>Integration among professionals</i>	x	x	"And so the integration among professions whether it's physicians, or even the social and health workers that we don't include many times ...in teams ...a shared training and shared values." (N3) "...a team made of people who are there because they want to be there, that helps." (R2)
<i>Spaces for sharing</i>	x	x	"And then perhaps in creating spaces for sharing." (N7) "...these spaces also become a protective support from a moral point of view" (R2)
<i>Receiving confirmation: social recognition</i>	x	x	"This in some ways is a sign of recognition of the citizens, of the people we care for, towards nurses. It was felt so much with COVID, they were always talking about nurses. Now already a little less. That is probably one of the most motivating factors probably from this point of view for nurses, because they feel that their work, their profession, is useful and recognized by people. So definitely the social recognition of the profession." (N2) "...to be recognized and seen for one's inclinations, to have the opportunity to develop them, and then to be placed in a context where you can give the best of yourself, giving satisfaction to the others, because in any case ours is a helping profession, that we are fulfilled when people 'are feeling better.'" (R2)

Legend: N, Nurse; R, Representative of the association.

essential. Finally, the focus groups found morally competent those nurses who show dedication, commitment to what they do, and who assume the responsibilities associated with their role.

Strategies to support the development of nurses' moral competences

According to nurses, moral competence needs to be developed in basic and continuing education. Such education should be tailored to the problems faced by the nursing profession and updated to the most current issues. Being able to rely on continuous stimuli for reflection offered by colleagues, coordinators, and students is another essential strategy to promote the attitude of asking oneself questions and learning from experience.

Patients and nurses feel that opportunities for integration among professionals, where they can work together, understand the multidimensional nature of problems and address them each with their own perspectives, are important. These spaces and times for sharing (between nurses, between nurses and physicians, between teams and patients/families) should be recognized and not relegated to free time. Support should also be provided from the outside, through social recognition: when the profession is recognized, nurses are encouraged to invest in their own competences, including moral ones.

Discussion

This study aimed at filling knowledge gaps by exploring the characteristics, knowledge, skills and attitudes that a nurse should possess in order to be considered as morally competent, integrating the patients' perspective. In addition, the study aimed to explore the "softer" skills of care, including attributes and personality traits, in an era in which technological skills are prevailing, leaving less space to more humanistic and compassionate approaches: defining these competences is considered a prerogative of such professions, especially in this challenging period, where some changes in the moral profile can be occurring. Moreover, having included patient representatives allowed a comprehensive view by giving voice to their daily experiences(17). Indeed, the 'emic perspective', i.e., that of stakeholders was included, considering

that moral competences cannot be understood without considering cultural and social contexts, subjective experiences, values, and meanings that people assign to these competences. Integrating the two perspectives ensures the creation of values focusing also on the protagonists of care, namely the patients(18).

The profile that emerged with respect to the morally competent nurse included several dimensions. In particular, the four characteristics express a professional and a relational dimension. Knowing how to deliver individualized care is considered to be an expression of moral competence because it leads nurses to search for data and knowledge about those for whom they are caring, their values and preferences(19, 20). 'Motivating', 'protecting' and 'setting an example', on the other hand, express the relationship with both patients and colleagues, confirming that nursing care is first and foremost an encounter between human beings(21). These characteristics support the understanding of the moral stress experienced by nurses when they cannot act consistently with expectations due to a lack of time, toxic or hostile work environments(11). In addition, these characteristics express a performance that is visible not only to the nurses themselves but also to patients and their families, and on which it is needed to activate reflections, strategies and support concerning their continuous development, when it results to be suboptimal performance.

The knowledge that nurses should possess is not described in detail: participants mention philosophical, ethical, psychological, humanistic, and legal disciplines without, however, dwelling on the content. These are subjects generally offered by the nursing program, although their harmonization with respect to credits, learning objectives, teaching methodologies and expected outcomes would be needed, considering that overall, at the European level, our students are found to be poorly prepared on such dimensions, as technical-procedural aspects tend to be privileged(8).

Among the skills, those related to understanding and the relationships with others were highlighted in both focus groups: in line with the literature, moral competence requires skills to protect the vulnerability of others through moral sensitivity,

interactions, and flexibility(22). All these aspects were presented by the participants as linked to an 'empathetic' nurse. Such skills should be part of explicit nursing student preparation and assessment systems, as well as of ethical codes(9). Nurses suggest additional skills towards colleagues or students in distress, which are in fact the same skills they should develop in favor of patients, but focused on colleagues: the ability to ask for help and to activate resources to be supported in overcoming problems/difficulties through group or expert advice. While on the one hand it is understandable that patient representatives do not report these skills, which are taken for granted or are less visible to them, on the other hand this 'internal care' within the group towards those in distress, or as the ability to ask for help when in distress, is in line with the literature that emphasizes the importance of the work environment and climate in preventing moral stress(23). Moral competence involves sensitivity towards others – not exclusively towards patients; colleagues may also need support. Moreover, as it specifically activates each of us in putting our values/beliefs on the line, it can turn us into people who need help in nursing care: being able to rely on a group or hospital resources made available to deliver support can make all the difference. Among skills, nurses also point out the ability to identify priorities: choosing what to do first or next, and especially what to neglect – in times of resource scarcity, is a decision that has moral implications. Differences in prioritization can generate conflicts among nurses, confusion among patients, and loss of care deemed essential for some and less so for others (e.g., relationship)(24).

Finally, the two focus groups of nurses agree on attitudes, describing a nurse who is continuously learning, shows dedication, and demonstrates a willingness to take responsibility. The literature, too, has repeatedly underlined the need for nurses to be reflective practitioners(25): on the one hand, such attitudes nurture moral competence and, on the other, they express it visibly. Teaching them to be reflective should be a priority in our education systems – sometimes too procedure- and technique-oriented(8).

The strategies suggested to support the moral competence of nurses are the typical ones (training

and teamwork) already reported in the literature(3,26); however, these strategies should rely on a formal space, valued by hospitals and recognized. Continuing education or reflection on practice does not always take place during duty hours; nurses are often required to use their free time for these development activities. Being recognized as valuable professionals, moreover, is considered to provide important support, as it encourages continuous deepening(27); organizations and society need to understand that investing in continuous education and support of the nursing personnel, who spend more time than any other professional near the patient, will benefit them and promote their safety and well-being.

Limitations

The study has several limitations. Nurses and representatives of patients' associations linked to researchers' context were included: additional focus groups at the national level could broaden this perspective. Furthermore, including more patients' associations that also reflect other health issues could ensure a more comprehensive view. Keeping the two focus groups separate facilitated free discussion by participants, who were likely to feel comfortable; however, a single focus group may further develop the understanding of the matter and provide integrated results. Finally, from a conceptual point of view, moral and ethical competence were not divided in their meaning, but considered as a broader conceptualization.

Conclusions

We conducted a qualitative study where two different perspectives were combined: that of nurses and that of the representatives of patients. Overall, the emerging profile is that of a nurse capable of fully developing the professional and relational competences expected in the scope of practice. When it comes to knowledge, skills and attitudes that nurses should possess to be morally competent, it became clear that they all revolve around three important concepts: communication, understanding and relationships with others. The development of moral competences should be continuously promoted with appropriate tools, as formal continuing education, on-the-job spaces for reflection and hospital services devoted to supporting nurses

in dealing with critical issues/dilemmas; however, social recognition has also been identified by both groups as capable of promoting moral competence. Being recognized by society promotes a feeling of respect towards nurses, thus encouraging them to keep developing their competences, including moral ones.

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ATTITUDES OF HEALTHCARE WORKERS TOWARDS DISABLED WOMEN, AFFECTING FACTORS AND ETHICAL DIMENSION: A DESCRIPTIVE AND CROSS-SECTIONAL STUDY

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Abstract: This study was conducted descriptively and cross-sectionally to determine the attitudes of healthcare professionals towards disabled women, the factors affecting them, and to evaluate their ethical dimensions. This descriptive study was conducted between 08/01/2022 and 10/31/2022 with midwives, nurses, and doctors working at the hospitals in Kahramanmaraş/Turkey. The sample size of the study was calculated with G*Power, and 307 healthcare professionals were included in the study. The research data were collected with the Personal Information Form and the Disabled Woman Attitude Scale. The data were analyzed with the SPSS for Windows 22.0 statistical package program. The total mean age of the participants was 33.60 ± 7.51 , the mean score of the disabled women and their private lives sub-dimension was 23.97 ± 5.72 , the mean score of the disabled women and disadvantages sub-dimension was 12.68 ± 4.37 , the mean score of the disabled women and social support sub-dimension was 14.88 ± 3.33 , the mean score of the disabled women and gender sub-dimension was 9.33 ± 3.18 and the total mean score of the scale was 60.87 ± 13.17 . In this study, it was observed that the attitudes of health workers towards disabled women were positive and that receiving training for disabled individuals and gaining experience in the care and treatment of disabled individuals positively affected the attitudes towards disabled women.

Keywords: disabled woman, doctor, ethics, midwife, nurse

Actitudes de los profesionales de la salud hacia las mujeres con discapacidad, factores que las afectan y dimensión ética: un estudio descriptivo y transversal

Resumen: Este estudio se realizó de forma descriptiva y transversal para determinar las actitudes de los profesionales de la salud hacia las mujeres con discapacidad y los factores que las afectan, y evaluar sus dimensiones éticas. Este estudio se llevó a cabo entre el 1 de agosto y el 31 de octubre de 2022 con matronas, enfermeras y médicos que trabajaban en los hospitales de Kahramanmaraş, Turquía. El tamaño de la muestra del estudio se calculó con G*Power, e incluyó a 307 profesionales de la salud. Los datos de la investigación se recopilaron con el Formulario de Información Personal y la Escala de Actitudes hacia la Mujer Discapacitada. Los datos se analizaron con el programa estadístico SPSS para Windows 22.0. La media de edad total de las participantes fue $33,60 \pm 7,51$; la de la subdimensión mujeres discapacitadas y su vida privada fue $23,97 \pm 5,72$; la de la subdimensión mujeres discapacitadas y desventajas fue $12,68 \pm 4,37$; la de la subdimensión mujeres discapacitadas y apoyo social fue $14,88 \pm 3,33$; la de la subdimensión mujeres discapacitadas y género fue $9,33 \pm 3,18$, y la media total de la escala fue $60,87 \pm 13,17$. En este estudio se observó que las actitudes de los trabajadores de la salud hacia las mujeres con discapacidad fueron positivas y que recibir formación sobre discapacidad y adquirir experiencia en el cuidado y tratamiento de personas con discapacidad afectaron positivamente las actitudes hacia las mujeres con discapacidad.

Palabras clave: mujer con discapacidad, médico, ética, matrona, enfermera

Atitudes de trabalhadores de cuidados à saúde em relação a mulheres com deficiências, fatores que influenciam e dimensão ética: um estudo descritivo e transversal

Resumo: Esse estudo foi realizado descritivamente e transversalmente para determinar as atitudes de profissionais de cuidados à saúde em relação a mulheres com deficiências, os fatores que as influenciam e avaliar suas dimensões éticas. Esse estudo descritivo foi realizado entre 01/08/2022 e 31/10/2022 com parteiras, enfermeira e médicos trabalhando nos hospitais em Kahramanmaraş, Turquia. O tamanho amostral do estudo foi calculado com G*Power e 307 profissionais de cuidados à saúde foram incluídos no estudo. Os dados da pesquisa foram coletados com o Personal Information Form e a Disabled Woman Attitude Scale. Os dados foram analisados com o programa do pacote estatístico SPSS for Windows 22.0. A idade média dos participantes foi $33,60 \pm 7,51$, o escore médio das mulheres deficientes e sua subdimensão vidas privadas foi $23,97 \pm 5,72$, o escore médio das mulheres deficientes e sua subdimensão prejuízo foi $12,68 \pm 4,37$, o escore médio das mulheres deficientes e sua subdimensão apoio social foi $14,88 \pm 3,33$, o escore médio das mulheres deficientes e sua subdimensão gênero foi $9,33 \pm 3,18$ e o escore médio total da escala foi $60,87 \pm 13,17$. Nesse estudo observou-se que as atitudes de trabalhadores de cuidados à saúde em relação a mulheres com deficiências foram positivas e que receber treinamento para indivíduos com deficiência e adquirir experiência no cuidado e tratamento de indivíduos com deficiência afetou positivamente as atitudes em relação a mulheres com deficiência.

Palavras chave: mulheres deficientes, médico, ética, parteira, enfermeira

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Introduction

Disability is a condition that is congenital or acquired, significantly restricts an individual's life functions for any reason and also affects physical, mental, psychological, and social reasoning(1). With the increase in the world population, and chronic diseases, the disabled population is also increasing day by day. While the ratio of disabled people to the world population is estimated to be 15%, it is reported that 80% of disabled people live in developing countries(2,3). According to the results of a comprehensive research conducted in 2002 on disability in our country, 12.29% of the total population consists of disabled individuals(4). In the 2015 report of the Türkiye Statistical Institute (TUSI), it was reported that the rate of disabled people is 5.9% for men and 7.9% for women(5). According to the report published by the Prime Ministry Disabled People Administration, it was stated that the ratio of female disabled individuals to the total population is 13.4%, 44.5% of disabled women are married and 40% are of reproductive age(4).

Disabled individuals constitute a disadvantaged group in society. Disabled women are exposed to both the negative situation stemming from being disabled and the disadvantages and gender discrimination brought by being a woman(6,7). It is reported that female disabled individuals have lower rates of participation in education and work life and utilization of health care services compared to men, the level of poverty is higher(2).

Disabled women need more support, education and care from health personnel than male disabled individuals due to their reproductive functions. In addition, pregnancy planning, the pregnancy process, birth and the postpartum period are of special importance for these women (8). However, many physically disabled women cannot access the health services they need due to various obstacles such as environmental and physical limitations, lack of education and economic difficulties(9,10). Disabled women not only face financial and physical obstacles in accessing health services, but also are exposed to discriminatory and disrespectful behaviors of health workers. A systematic review of qualitative studies to determine the barriers that women

with disabilities face in accessing health services revealed that these women face a variety of sociocultural (incorrect assumptions, negative attitudes, being ignored, being judged, violence, abuse, insults, rudeness, and low health literacy), financial (poverty, unemployment, high transportation costs), structural (lack of insurance coverage, inaccessible equipment and transportation, lack of information, lack of access to information, lack of transparency), and communication problems(11). When evaluated ethically, the attitudes of health professionals towards women with disabilities should be considered from a human rights perspective. Access to health services for women with disabilities requires an approach based not only on physical treatment but also on psychosocial support and social equality(12). In this context, the attitudes of health professionals must be shaped by respecting the dignity and independence of individuals with disabilities. The ethical responsibilities of healthcare professionals in the care of disabled women should include not only physical recovery but also supporting the individual's social role, identity, and sense of self(13).

The attitudes of health workers should be developed based on professional codes of ethics, ethical principles, and an empathetic approach, as these attitudes will facilitate the access of women with disabilities to health services while also contributing to the adoption of a more equitable approach in society.

The attitudes of healthcare professionals towards disabled women are very important in disabled women's application to healthcare institutions and in receiving quality healthcare services. The people closest to disabled women are healthcare professionals. There are studies in the literature examining the attitudes of students studying in the field of health and healthcare professionals towards disabled individuals(14-18). However, no study has been found in which the attitudes of healthcare professionals towards disabled women, the factors affecting them, and the attitudes of healthcare professionals towards disabled women are investigated and their ethical dimensions are discussed together. In this context, it is thought that our study is original and will make a positive contribution to the literature, disabled

women and health workers. In this context, it is thought that our study is original and will contribute positively to the literature, disabled women and healthcare professionals.

Aim

This study was conducted to determine the attitudes of health care workers towards women with disabilities and the influencing factors and to evaluate the ethical dimension of the attitudes of health care workers towards women with disabilities.

Research questions

1. What are the attitudes of healthcare professionals towards disabled women?
2. What factors affect the attitudes of healthcare professionals towards disabled women?
3. What is the ethical dimension of the attitudes of healthcare professionals towards disabled women?

Methods

Type of the research

This research is a descriptive and cross-sectional study.

Place and time of the research

The study was conducted between 01.08.2022 and 31.10.2022 in Kahramanmaraş, City Hospital, State Hospital and Maternity and Children's Hospital located in southeastern Turkey.

Universe and sample of the research

The universe of the research consists of 1518 midwives, nurses and doctors working in the relevant hospitals. The sample size universe of the research was calculated using the known sample calculation formula. As a result of the calculation, the sample size was determined to be 307, and the study was conducted with 307 midwives, nurses and doctors. Healthcare workers who agreed to participate in the study, health care workers who worked in the hospital where the study was

conducted and who agreed to participate in the study were included in the study. Healthcare workers who were on leave, on sick leave, working in another institution with an assignment during the data collection period, who gave inconsistent answers and who did not want to participate in the study were not included in the study.

Data collection tools

The data in the study were collected with the Personal Information Form, which questions the socio-demographic characteristics of the participants and the Disabled Woman Attitude Scale (DWAS).

The personal information form was prepared by the researchers by reviewing the literature(19-22). It consists of a total of 12 questions, including personal information (9 questions) and the status of being a relative of a disabled person, their status of receiving education regarding the care of disabled individuals, and their experiences regarding the care and treatment process (4 questions).

DWAS is a scale that determines the attitudes of healthcare professionals and students towards disabled women. DWAS is a 5-point Likert-type scale consisting of 17 items and 4 factors developed by Yılmaz and Ören (2021)(23). Each item in DWAS is scored from 1 to 5. The statements were asked to be rated between 1 (strongly agree) and 5 (strongly disagree). The number 1 indicates high negativity towards completely agreeing, and the number 5 indicates completely disagree indicates low negativity. The lowest score received from DWAS is 17, and the highest score is 85. A low score indicates high negativity for disabled women, while a high score indicates low negativity. The Cronbach's alpha value of the scale was found to be 0.817 and the test-retest correlation value was found to be 0.992(23). In this study, Cronbach's alpha coefficient was found to be 0.91.

Data collection

Data were collected by the assistant researcher using the face-to-face interview method. Before the survey was administered, the health worker was informed about the study and written and

verbal consent was obtained. The surveys were filled out at the participants' convenience and took an average of 10 minutes.

Analysis of the data

Data were analyzed using the Statistical Programme for Social Science 22.0 (SPSS) program. In the analysis of the study, frequency, percentage, mean, and standard deviation statistical methods were used as descriptive statistics. The Shapiro-Wilk test was performed and it was determined that the data did not show normal distribution. Since the data did not show a normal distribution, analysis was performed with nonparametric tests. In the comparison of dependent and independent variables, the Mann-Whitney-U test was used to evaluate the difference between the means of 2 groups, and the Kruskal-Wallis test was used to evaluate the difference between the means of 3 or more groups. The statistical significance value was taken as $p < 0.05$.

Ethics approval and consent to participate

The research was approved by Cukurova University Faculty of Medicine Non-Interventional Clinical Research Ethics Committee on June 2022, 50/3. Institutional permission from the hospitals; written and verbal informed consent was obtained from the participants. Permission to use the scale has been obtained. The study was carried out in accordance with the Declaration of Helsinki.

Findings

The socio-demographic characteristics of the healthcare workers participating in the study are shown in Table 1. Accordingly, the average age of the healthcare workers was 33.60 ± 7.51 (min:24, max:60), 52.8% were 31 years old and above, 77.2% were female, 59.3% were married, 52.8% had children, 73.0% were nurses, 52.8% had a bachelor's degree, and 59.0% had worked for 6 years or more. It was also determined that 70.7% did not have a disabled relative, 53.7% did not receive training on the care of disabled individuals during their education, 73.3% did not receive in-service training on the care of disabled individuals while working, 90.2% did not receive training to facilitate communication with

disabled individuals or caregiving, and 65.1% did not have experience in the care, monitoring or treatment of disabled individuals (Table 1).

Table 1. Descriptive Characteristics of Healthcare Workers (N: 307)

Descriptive Characteristics	n	%
Age average 33.60 ± 7.51		
30 years and below	145	47.2
31 years and above	162	52.8
Gender		
Female	237	77.2
Male	70	22.8
Marital status		
Married	182	59.3
Single	125	40.7
Children		
No children	145	47.2
Have children	162	52.8
Occupation		
Physician	27	8.8
Midwife	56	18.2
Nurse	224	73.0
Educational status		
High school-Associate degree	97	31.6
Undergraduate	162	52.8
Postgraduate	48	15.6
Working period		
5 years and below	126	41,0
6 years and above	181	59,0
Having a relative with a disability		
Yes	90	29.3
No	217	70.7

Having received training on caring for disabled people during education		
Yes	142	46.3
No	165	53.7
Having received in-service training on caring for disabled people while working		
Yes	82	26.7
No	225	73.3
Having received training to communicate with disabled people or to facilitate caring for them		
Yes	30	9.8
No	277	90.2
Having had experience in caring for, monitoring or treating disabled individuals		
Yes	200	65.1
No	107	34.9

Table 2 shows the distribution of the participants' mean scores from the DWAS and its sub-dimensions. It was determined that the health workers' mean DWAS women with disabilities and their private lives sub-dimension score was 23.97 ± 5.72 , their mean disabled women and disadvantages sub-dimension score was 12.68 ± 4.37 , their mean disabled women and social support sub-dimension score was 14.88 ± 3.33 , their mean disabled women and gender sub-dimension score was 9.33 ± 3.18 , and their mean total scale score was 60.87 ± 13.17 (Table 2).

Table 2. Distribution of mean scores of healthcare professionals from DWAS and its sub-dimensions (N: 307)

DWAS and Sub-dimensions	Min	Max	X $\pm$ SD
Disabled Women and Their Private Lives	6	30	23.97 ± 5.72
Disabled Women and Disadvantages	4	20	12.68 ± 4.37
Disabled Women and Social Support	4	20	14.88 ± 3.33
Disabled Women and Gender	3	15	9.33 ± 3.18
DWAS Total Score	17	85	60.87 ± 13.17

X: Average, SD: Standard Deviation, Min: Minimum, Max: Maximum.

When the DWAS subdimensions and total scores of the participants were compared according to the sociodemographic characteristics, it was determined that there was a significant difference between the participants' ages and disabled women and private lives, disabled women and social support subdimensions, between occupation and disabled women and social support, disabled women and gender subdimensions, between educational status and disabled women and social support, disabled women and gender subdimensions, and between years of employment and disabled women and gender subdimensions ($p \leq 0.05$). Between the status of receiving training on the care of disabled people during education and disabled women and private lives, disabled women and disadvantages, disabled women and social support, disabled women and gender subdimensions and DWAS total score; between the status of receiving in-service training on the care of disabled people while working and disabled women and social support, disabled women and gender subdimensions and DWAS total score; It was determined that there was a significant difference between the status of receiving education that will facilitate communication or caregiving

Table 3. Distribution of DWAS total and sub-dimensions mean scores of healthcare workers according to their descriptive characteristics (N: 307)

Descriptive Characteristics	DWAS				
	Disabled women and their private lives	Disabled women and disadvantages	Disabled women and social support	Disabled women and gender	Total
	X±SD	X±SD	X±SD	X±SD	X±SD
Age					
30 years and below	25.05±5.05	12.91±4.44	15.32±3.16	9.20±3.18	62.49±12.15
31 years and above	25.05±5.05	12.48±4.31	14.48±3.43	9.45±3.19	59.43±13.91
p	0.002	0.462	0.020	0.316	0.061
Z	-3.031	-.735	-2.333	-1.002	-1.875
Gender					
Female	23.86±5.88	12.84±4.37	14.93±3.37	9.46±3.23	61.10±13.50
Male	24.35±5.19	12.14±4.34	14.71±3.20	8.90±2.99	60.11±12.06
p	0.820	0.238	0.427	0.133	0.378
Z	-.227	-1.181	-.794	-1.501	-.882
Marital status					
Married	23.74±5.68	12.85±4.20	14.89±3.32	9.53±3.07	61.03±12.74
Single	24.30±5.79	12.43±4.60	14.86±3.35	9.04±3.33	60.64±13.83
p	0.282	0.470	0.867	0.187	0.797
Z	-1.075	-.723	-.167	-1.319	-.257
Child					
No child	24.24±5.70	12.46±4.56	14.93±3.36	9.04±3.22	60.68±13.53
Child Yes	23.73±5.75	12.88±4.19	14.83±3.31	9.59±3.13	61.04±12.88
p	0.413	0.412	0.659	0.093	0.935
Z	-.819	-.821	-.659	-1.681	-.081
Profession					
Physician	24.88±3.60	11.81±4.39	13.40±3.02	8.51±2.47	58.62±8.48
Midwife	22.82±6.62	13.35±4.71	15.16±3.54	10.48±3.65	61.82±16.01
Nurse	24.15±5.67	12.62±4.27	14.99±3.28	9.15±3.07	60.91±12.87
p	0.540	0.274	0.015	0.005	0.212
KW	1.233	2.587	8.441	10.764	3.102
Education Status					
High School-Associate Degree	23.31±6.67	12.82±4.73	14.79±3.81	9.18±3.57	60.12±16.08
Undergraduate	24.29±5.17	12.66±4.09	14.99±3.07	9.44±2.96	61.38±11.43
Postgraduate	24.22±5.45	12.47±4.59	14.68±3.16	9.29±3.11	60.68±12.31
p	0.822	0.697	0.500	0.868	0.518
KW	0.392	0.722	1.387	0.282	1.316

Working Period					
5 years and below	24.10±5.60	12.79±4.40	14.96±3.33	8.92±3.25	60.77±12.84
6 years and above	23.88±5.82	12.60±4.35	14.82±3.33	9.62±3.10	60.95±13.43
p	0.958	0.655	0.673	0.027	0.690
Z	-.053	-.447	-.422	-2.208	-.398
Having a disabled relative	24.70±4.50	12.64±4.36	15.44±2.88	9.54±3.14	62.33±11.67
Yes	23.67±6.14	12.70±4.38	14.64±3.47	9.25±3.20	60.27±13.73
No					
p	0.548	0.982	0.087	0.602	0.651
Z	-.601	-.023	-1.713	-.522	-.651
Receiving training on caring for disabled people during education					
Yes	25.47±4.33	13.31±4.57	15.50±2.93	9.83±3.33	64.14±11.06
No	22.67±6.43	12.13±4.12	14.34±3.55	8.90±2.99	58.07±14.19
p	0.000	0.033	0.017	0.020	0.002
Z	-3.921	-2.133	-2.382	-2.331	-3.138
Receiving in-service training for caring for disabled people while working					
Yes	24.96±4.50	13.46±4.60	15.75±3.30	10.00±3.28	64.18±12.30
No	23.61±6.08	12.40±4.26	14.56±3.28	9.09±3.12	59.67±13.30
p	0.184	0.096	0.011	0.046	0.021
Z	-1.329	-1.664	-2.529	-1.994	-2.304
Communication with disabled individuals or receiving training that will facilitate caregiving					
Yes	25.63±5.09	14.00±4.75	15.93±3.52	10.23±3.829.24±3.10	65.80±14.81
No	23.79±5.77	12.54±4.31	14.76±3.29		60.34±12.90
p	0.071	0.095	0.029	0.134	0.032
Z	-1.807	-1.669	-2.187	-1.497	-2.139
Experience of caring for. Monitoring or treating disabled individuals					
Yes	24.89±4.81	13.06±4.25	15.30±3.01	9.68±3.12	62.93±11.39
No	22.26±6.83	11.98±4.52	14.10±3.74	8.69±3.20	57.03±13.17
p	0.002	0.059	0.023	0.015	0.009
Z	-3.129	-1.887	-2.281	-2.433	-2.614

X: Average, SD: Standard Deviation, Z: Mann Whitney U test, KW: Kruskal Wallis Test.

with disabled people and the disabled women and gender sub-dimensions and the DWAS total score, and between the status of having experience in caring for, monitoring or treating disabled individuals and the disabled women and their private lives, disabled women and social support, disabled women and gender sub-dimensions and the DWAS total score ($p \leq 0.05$) (Table 3).

Discussion

This study aimed to determine the attitudes of healthcare professionals towards disabled women, and also to reveal whether the attitudes of the participants differed in terms of some variables. In our study, the total DWAS score average of healthcare professionals was found to be 60.87 ± 13.17 (Min:17- Max:85). Considering that the lowest scale score was 17 and the highest scale score was 85, it can be said that the healthcare professionals participating in the study had a positive attitude towards disabled women. Similarly, Edis and Ketten reported in their study that healthcare professionals have positive attitudes towards disabled women (24). Unlike our study, a study conducted in Nepal revealed that healthcare professionals have negative attitudes towards disabled women and that their knowledge and skills regarding the care of these women are inadequate. In a study examining the attitudes of healthcare professionals towards disabled individuals, it was found that these attitudes are generally positive (18). Apaydın and Barış (2021) also reported that healthcare professionals have positive attitudes towards disabled individuals (17). In addition, another study conducted with physicians and nurses indicated that there is a moderately positive attitude towards disabled individuals (26). According to our study findings, although young participants have higher DWAS scores than older age groups, no significant relationship was found between age and DWAS score average ($p > 0.05$). Similarly, in the most comprehensive study conducted in our country to measure attitudes towards the disabled, it was reported that young people have more positive attitudes than older people (27). Similar results were found in another study conducted in our country (26).

In our study, although there was no significant difference between the gender of the participants

and the DWAS score average, it was observed that women had more positive attitudes than men. When the literature was examined, studies conducted showed that there was no difference in the attitudes of both genders towards the disabled (15,28). A study conducted in our country showed that there was a significant difference between the gender of healthcare professionals and the DWAS score averages and that the score averages of women were higher than those of men (24). Similar studies show that women have more positive attitudes towards disabled individuals than men (16,28,29). The reason why women have more positive attitudes towards disabled women may be due to the fact that they generally adopt a more sensitive and supportive approach towards disabled individuals due to factors such as empathy, social roles, personal experiences and awareness. In our study, no significant relationship was found between the marital status and number of children of the participants and the DWAS score average ($p > 0.05$). Similar to our study, Çıtlı and Kılıç (2019) also reported that the participants' status of marriage and having children did not have a significant effect on their attitudes towards disabled individuals (26).

In our study, no significant relationship was found between the participants' professions and the DWAS score average, and it was determined that midwives had a more positive attitude towards disabled women than nurses and doctors ($p > 0.05$). In a study conducted with healthcare professionals, it was determined that the profession did not affect attitudes towards disabled women. In addition, in the same study, it was determined that midwives and nurses had a more positive attitude towards disabled women than doctors and other healthcare professionals (24). It is thought that this situation is because the majority of nurses and midwives are women and therefore have better empathy with disabled women.

There was no significant relationship between the participants' education level and the DWAS score average ($p > 0.05$). The study conducted by Akça et al. (2024) with healthcare professionals also showed that there was no statistically significant difference between education level and attitudes towards disabled people (28). The literature is similar to our findings (24,26).

There was no significant relationship between the length of service of healthcare professionals and the DWAS score average ($p>0.05$). In another study, there was no statistically significant difference between the length of service and attitudes towards disabled women(24). Contrary to our study, there are also studies showing that there is a significant difference between the length of service and the attitude towards disabled individuals(26,28).

In our study, there was no significant relationship between the participants' status of having a disabled relative and the DWAS score average ($p>0.05$). However, the attitudes of disabled women were found to be higher in participants with disabled relatives than in those without disabled relatives. In the study by Edis and Keten (2024), it was found that healthcare professionals who have a disabled individual in their family have lower attitudes towards disabled women than those who do not(24). In addition, Kılıç and Çıtlı (2019) showed that nurses and doctors who have a disabled individual in their family have lower attitudes towards disabled individuals than those who do not(26). In a study conducted to determine the attitudes of healthcare professionals towards disabled individuals, it was stated that healthcare professionals who have a disabled individual in their family or close circle have lower attitudes towards disabled individuals than those who do not(18). Some studies show that interacting with disabled individuals positively affects attitudes towards these individuals(25,30). In our study, it was determined that participants who have a disabled relative have more positive attitudes towards disabled women than those who do not have a disabled relative. This situation reflects the effect of interaction with disabled individuals. In addition, a significant relationship was found between the status of having experienced care, monitoring, or treatment of disabled individuals and the DWAS score averages in our study ($p<0.05$). The mean DWAS scores of those who had experience in caring for, monitoring, or treating disabled individuals were found to be higher than those who did not have experience.

A notable finding in our study is that education is an important factor in the attitudes of healthcare professionals towards disabled women. In this

study, it was observed that there was a statistically significant difference between the average DWAS scores and the status of receiving training on the care of disabled individuals during education, receiving training on the care of disabled individuals while working, and receiving training to communicate with disabled individuals or to facilitate caregiving. Participants who received training on the care of disabled individuals during education, received in-service training on the care of disabled individuals while working, and received training to communicate with disabled individuals or to facilitate caregiving showed more positive attitudes towards disabled women. In the study conducted by Ayyıldız and Ulupınar (2019) with nurses working in primary care, it was reported that more than half of the nurses did not receive training on the disabled during their education(31). In the study conducted by Apaydın and Barış (2021) to determine the attitudes and awareness of healthcare professionals towards disabled individuals, it was determined that 73.4% of the participants did not receive any courses, seminars, or training on working with disabled individuals. In the same study, 80.4% of the participants reported that they wanted to receive training for disabled individuals(17). There are studies in the literature indicating that receiving previous training on disability has positive effects on attitudes towards disabled individuals(14,32,33). In the study by Geçkil et al. (2017), it was reported that empathy activities implemented to understand disabled individuals positively affected the attitudes of student nurses towards disabled individuals(34). In a study conducted in Istanbul, it was determined that 7 out of 10 healthcare professionals had difficulty communicating with disabled individuals and that the majority of healthcare professionals had not received any training on disabled individuals either before or in the institution where they worked(17). In the systematic review conducted by Evans et al. (2023) to investigate the effects of educational interventions on the attitudes and empathy levels of nursing and medical students towards disabled individuals, the effectiveness of the disabled health course, the disability education module with bedside training and the wheelchair workshop intervention was evaluated. At the end of the study, it was shown that the disabled health course, which uses the emotional learning

method based on transformative learning theory, significantly improves attitudes towards disability among nursing students(35). In this context, it is of great importance that education programs in the field of health increase awareness about providing respectful and equal services to individuals with disabilities. Pre-graduate and post-graduate education programs help healthcare professionals develop their attitudes by providing them with knowledge and skills on how to communicate and care for individuals with disabilities more effectively.

The attitudes of healthcare professionals towards women with disabilities are of great importance in providing healthcare services in a fair, equal and respectful manner. According to ethical principles, every individual has equal rights. However, women with disabilities have to struggle not only with physical disabilities but also with gender-based discrimination and social prejudices. This makes it difficult for them to access healthcare services and can result in a violation of their right to health(36-38). Healthcare professionals need to see women with disabilities as individuals, not only from a medical perspective but also from an ethical perspective, showing human respect. The insensitivity and prejudices in the approach of healthcare professionals to individuals with disabilities violate the principle of autonomy. Autonomy, one of the medical ethical principles, emphasizes the right of individuals to make their own healthcare decisions; however, women with disabilities may have difficulty exercising these rights due to the exclusionary attitudes of healthcare professionals towards them(39-41). Justice is one of the fundamental principles in health ethics. Women with disabilities are often excluded and ignored from society due to both their gender and their disability. This creates significant obstacles to their access to health services. Therefore, it is not only a professional responsibility but also an ethical obligation for health professionals to approach individuals with disabilities based on empathy and understanding. This approach will contribute to eliminating inequalities in health services(37,41,42). In addition, health professionals need to receive training on disability to prevent the violation of the rights of individuals with disabilities in social and health services(40,43). This

training increases the awareness of healthcare professionals, enables them to adopt a more ethical approach and ensures that women with disabilities can fully benefit from healthcare services. As a result, an ethically correct attitude in healthcare services will contribute to the achievement of social justice by ensuring that women with disabilities are treated based on equal rights, with respect and empathy.

Research limitations

This study is limited to midwives, nurses, and doctors working in secondary healthcare institutions in Adana, Turkey, and can only be generalized to this group. In addition, the fact that the study was conducted only in secondary health institutions, not all health personnel were included in the study, and the socio-economic, and educational level of the participants constitute the limitations of the study.

Conclusion

The attitudes of health workers towards women with disabilities are very important in ensuring that women with disabilities receive quality and qualified care from health services. The attitudes of health workers towards women with disabilities are directly related to basic ethical principles such as gender equality, accessibility and equal access to health services. Individuals with disabilities encounter various difficulties while benefiting from health services, and this situation can become even more complicated for women. The obstacles experienced by women with disabilities in accessing health services are shaped by both physical and social obstacles. In this context, the ethical evaluation of the attitudes of health workers towards women with disabilities plays an important role both in ensuring that professional health practices are compatible with human rights and in increasing the quality of health services. In this context, health personnel should exhibit a holistic approach in line with ethical principles in the care of women with disabilities and fulfill their professional responsibilities for all patients. In our study, the total mean score of DWAS used to determine the attitudes of healthcare professionals towards disabled women was found to be 60.87 ± 13.17 (Min:17-Max:85). Considering that the lowest

scale score was 17 and the highest scale score was 85, it can be said that healthcare professionals participating in the study had a positive attitude towards disabled women. It was determined that those who received in-service training on the care of disabled individuals during their education and while working, received training on communicating with disabled individuals or facilitating caregiving, and had experience in the care, monitoring, or treatment of disabled individuals, had a more positive attitude towards disabled women. It can be suggested that the education curricula of healthcare professionals be updated and supported with various teaching methods regarding the treatment and care of disabled individuals, and regular in-service training be provided in order to meet the educational needs of healthcare professionals. Finally, it is also suggested that qualitative research be conducted to examine the attitudes of healthcare professionals towards disabled women in more depth.

Competing interests

The author declare no competing interests.

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CULTURAL INFLUENCE IN FASHION MARKETING OF HEALTHCARE PRODUCTS: A CASE STUDY OF GB, PAKISTAN

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Abstract: This study examines the cultural factors influencing fashion tastes and marketing techniques of healthcare products in Gilgit-Baltistan (GB), Pakistan, emphasizing the region's distinctive amalgamation of tradition, traditional values, and contemporary influences. This research conducts a qualitative analysis of 120 theme responses from local participants to investigate the influence of cultural heritage, social norms, and technological advancements—specifically media and internet shopping—on fashion preferences and purchasing patterns of healthcare products. The findings underscore the pivotal influence of cultural identity and traditional values on fashion preferences, especially with modesty, community involvement, and local festivals. The study examines the increasing impact of social media and international fashion trends, as well as the obstacles and potential for local enterprises in incorporating cultural heritage into the fashion marketing of healthcare products. The study emphasizes the necessity of a balanced strategy that honors cultural traditions while integrating contemporary trends, offering insights for firms to effectively connect with local consumers. Ultimately, it proposes future study avenues centered on sustainability, digital transformation, and cross-cultural comparisons to further the comprehension of fashion marketing of healthcare products in culturally diverse areas such as Gilgit-Baltistan for healthcare products marketing.

Keywords: cultural heritage, fashion preferences, marketing strategies, modern influences, healthcare products

Influencia cultural en el marketing de moda de productos sanitarios: un estudio de caso de GB, Pakistán

Resumen: Este estudio examina los factores culturales que influyen en los gustos de moda y las técnicas de marketing de productos sanitarios en Gilgit-Baltistán (GB), Pakistán, destacando la distintiva fusión de tradición, valores tradicionales e influencias contemporáneas de la región. La investigación realiza un análisis cualitativo de 120 respuestas temáticas de participantes locales para investigar la influencia del patrimonio cultural, las normas sociales y los avances tecnológicos —específicamente, las compras en medios de comunicación e internet— en las preferencias de moda y los patrones de compra de productos sanitarios. Los hallazgos subrayan la influencia crucial de la identidad cultural y los valores tradicionales en las preferencias de moda, especialmente respecto de la modestia, la participación comunitaria y las festividades locales. Examina el creciente impacto de las redes sociales y las tendencias internacionales de moda, así como los obstáculos y el potencial de las empresas locales para incorporar el patrimonio cultural en el marketing de moda de productos sanitarios. Enfatiza la necesidad de una estrategia equilibrada que honre las tradiciones culturales, a la vez que integra las tendencias contemporáneas, ofreciendo perspectivas para que las empresas conecten eficazmente con los consumidores locales. Finalmente, propone futuras líneas de estudio centradas en la sostenibilidad, la transformación digital y las comparaciones interculturales, para profundizar en la comprensión del marketing de moda de productos sanitarios en zonas culturalmente diversas, como Gilgit-Baltistán.

Palabras clave: patrimonio cultural, preferencias de moda, estrategias de marketing, influencias modernas, productos sanitarios

Influência cultural no marketing de moda de produtos de cuidados à saúde: um estudo de caso em GB, Paquistão

Resumo: Esse estudo examina os fatores culturais que influenciam os gostos de moda e técnicas de marketing de produtos de cuidados à saúde em Gilgit-Baltistan (GB), Paquistão, enfatizando a singular fusão de tradição, valores tradicionais e influências contemporâneas daquela região. Essa pesquisa realiza uma análise qualitativa de 120 respostas temáticas de participantes locais para investigar a influência da herança cultural, normas sociais e avanços tecnológicos —especificamente compras pela mídia e internet— nas preferências de moda e padrões de compra de produtos de cuidados à saúde. Os achados destacam a influência crucial da identidade cultural e valores tradicionais nas preferências de moda, especialmente no que diz respeito à modéstia, ao envolvimento comunitário e aos festivais locais. O estudo examina os impactos crescentes da mídia social e tendências de moda internacional, bem como os obstáculos e potencial para empresas locais incorporarem herança cultural no marketing de moda de produtos de cuidados à saúde. O estudo enfatiza a necessidade de uma estratégia equilibrada que honre tradições culturais ao integrar tendências contemporâneas, oferecendo insights para empresas se conectarem com consumidores locais. Em última análise, propõe futuras linhas de estudos centradas em sustentabilidade, transformação digital e comparações interculturais para aprofundar a compreensão do marketing de moda de produtos de cuidados à saúde em áreas culturalmente diversas tais como o marketing de moda de produtos de cuidados à saúde em Gilgit-Baltistan.

Palavras chave: herança cultural, preferência de moda, estratégias de marketing, influências modernas, produtos de cuidados à saúde

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Introduction

The complex interplay between culture and consumer behavior is a vital element in the formulation of marketing strategies for fashion of healthcare products. In regions such as Gilgit-Baltistan (GB), Pakistan, where cultural legacy is profoundly embedded and unique, it is imperative to possess a comprehensive understanding of these influences. Gilgit-Baltistan is widely recognized for its diverse ethnic communities, rich traditions, and unique social dynamics. Cultural components significantly influence consumer decisions, purchasing behavior, and brand perceptions, offering a compelling context for exploring the convergence of culture and fashion marketing of healthcare products(1).

This study examines the cultural elements influencing the fashion marketing of healthcare products in Gilgit-Baltistan. This project aims to examine how local cultures, values, and social norms affect consumer choices in the fashion industry of healthcare products. This will be achieved through qualitative interviews with persons located throughout the region. This study elucidates the complexities of consumer behavior in a culturally diverse region, providing insights that businesses and marketers can leverage to develop tailored strategies that resonate with the local audience(2).

This research contributes to the broader discourse on cultural diversity in fashion marketing of healthcare products and underscores the importance of context-specific strategies in an increasingly globalized industry. This study aims to offer insightful perspectives for academics and industry professionals interested in the complex relationship between culture and commerce in the fashion industry of healthcare product marketing. This is achieved by concentrating on the unique cultural landscape of Gilgit-Baltistan(3).

In a progressively interconnected world, comprehending the cultural aspects of fashion marketing of healthcare products transcends geographical limits, providing significant insights into global consumer behavior. The interaction between tradition and modernity in Gilgit-Baltistan reflects analogous dynamics in other culturally affluent areas, where heritage-inspired fashion selections

coexist with global trends. This study enhances local market strategies and provides broader applicability for international brands aiming to operate in culturally sensitive countries. This research analyzes the influence of social conventions, digital media, and changing consumer preferences on fashion trends of healthcare products within a unique yet internationally pertinent context, offering a framework to guide marketing efforts across many cultural environments. These findings may be especially advantageous for international fashion firms of the healthcare product industry, legislators, and scholars seeking to reconcile cultural authenticity with market-driven adaptation in an age of swift globalization(4).

Background and Problem

A primary problem in the fashion marketing of healthcare products in Gilgit-Baltistan is the region's infrastructural deficiencies, which impede accessibility and the delivery of fashion products of healthcare products. The remote terrain and underdeveloped retail networks limit the availability of different fashion options, forcing many consumers to depend on online shopping, which, despite its growth, encounters logistical challenges such as inconsistent delivery services and restricted internet access in rural regions. Moreover, generational disparities significantly influence fashion inclinations. Younger generations are increasingly swayed by global fashion trends via social media and digital platforms, whilst older generations typically favor traditional apparel that reflects cultural history and modesty. The generational divide poses a marketing problem, requiring firms to mix innovation with heritage to attract a diverse consumer base. Comprehending these limits is crucial for enterprises seeking to formulate culturally adaptable and sustainable fashion marketing strategies for healthcare products that address the distinctive socio-economic and demographic context of Gilgit-Baltistan(5).

Novelty of Study

This study provides a distinctive contribution by concentrating on the culturally affluent yet academically under-researched area of Gilgit-Baltistan (GB), Pakistan. This study contrasts with prior research that mostly focuses on fashion marketing

of healthcare products in urban and globally interconnected markets by exploring how cultural history, societal norms, and contemporary influences affect consumer behavior in a geographically isolated and diversified context. This research offers new insights into the interplay of tradition and modernity in fashion marketing of healthcare products, considering the region's unique socio-cultural context, with significant implications for local enterprises and broader cross-cultural marketing tactics. This study addresses a research gap, enhancing comprehension of consumer preferences in GB and contributing to the conversation on culturally ingrained marketing strategies in emerging economies(6).

Research objectives:

The research objectives of this study are structured around understanding the dynamic interplay between cultural heritage and evolving fashion trends of healthcare products in Gilgit-Baltistan. Specifically, the study aims to explore how deeply rooted cultural values shape individual fashion preferences and the extent to which traditional attire reflects cultural identity in everyday life and special occasions(7). Furthermore, it aims to investigate the impact of social norms and community expectations on the adoption of diverse fashion trends and brands in the region for healthcare products. The study examines the influence of media and technology, namely social media platforms and online shopping, on fashion awareness and purchasing behaviors, evaluating whether these digital factors reinforce or contest local cultural norms. This research seeks to elucidate the significance of cultural heritage in fashion marketing of healthcare products strategies and examine how local enterprises can incorporate traditional elements into their campaigns to align more effectively with the preferences and expectations of the regional populace(8).

Research Questions:

Cultural Values and Fashion Preferences

How do the cultural traditions and values of Gilgit-Baltistan influence your choices in clothing and fashion of healthcare products? Can you share specific examples of how traditional or modern attire

reflects cultural identity in your daily life or on special occasions?

Impact of Social Norms on Fashion Trends

In your opinion, how do social norms and community expectations shape the adoption of fashion trends of healthcare products in Gilgit-Baltistan? Are there particular styles or brands that are more acceptable or admired within your community?

Role of Media and Technology in Fashion Awareness

How have media and technology, such as social media platforms and online shopping, affected the fashion preferences and purchasing behaviors of people in Gilgit-Baltistan for healthcare products? Do you think these platforms represent or challenge local cultural influences?

Business Perspectives on Cultural Integration in Marketing

For local businesses or marketers, what role does cultural heritage play in promoting fashion-related healthcare products in Gilgit-Baltistan? How can fashion marketing of healthcare product campaigns better align with the cultural values and expectations of the local population?

Literature Review

Cultural Influence in Fashion Marketing

Cultural influence has been recognized as a crucial factor in customer behavior, particularly in fashion marketing of healthcare products. Culture shapes individual choices, attitudes, and perceptions, acting as a crucial factor in the styles and trends that attract different people. Fashion, as a reflection of identity, serves as an expression of personality and a medium for expressing cultural narratives. Research demonstrates that cultural values, encompassing traditions, norms, and rituals, significantly influence the adoption of fashion trends, since consumers are often drawn to fashions that align with their social and cultural identities(9). The globalization of fashion has engendered new dynamics, leading to tensions between the preservation of cultural heritage and the embrace of modern global trends. This connection is particu-

larly evident in diverse and culturally rich regions, where traditional attire coexists with contemporary influences. The rise of digital platforms and media has intensified the relationship between culture and fashion, enabling the rapid dissemination of global trends while also offering opportunities for cultural preservation and localized marketing. The integration of cultural insights into fashion marketing strategies for healthcare products, while significant, is inconsistent, highlighting the need for research that links cultural understanding with business realities. This analysis provides a basis for investigating the impact of cultural factors on fashion marketing techniques for healthcare products, focusing on the unique and under-explored area of Gilgit-Baltistan, Pakistan(1,10).

Cultural Values and Their Impact on Fashion Preferences

Cultural values serve as a foundational guide for individual and collective behaviors, significantly influencing preferences in fashion and attire. Theoretical theories, such as Hofstede's cultural dimensions, provide valuable insights into how individualism, collectivism, and power distance affect fashion tastes in various countries. Cultural hegemony and symbolic interactionism similarly highlight the power dynamics and social meanings embedded in clothing, illustrating how fashion serves as both a reflection and reinforcement of society's standards. Traditional and heritage-based garments often represent cultural identity, symbolizing values, history, and a connection to one's roots(11,12).

In regions like Gilgit-Baltistan, clothing selections are rooted in cultural traditions that embody unique ethnic and religious identities. Traditional attire functions as a manifestation of aesthetic choices and a marker of communal affiliation and social status. However, the influence of current trends and globalized fashion has started to alter these preferences, leading to a blend of traditional and modern styles. Case studies from similar culturally affluent regions demonstrate the considerable impact of cultural identification on consumer choices, as individuals often select clothes that embody their values while aligning with current trends(13). Comprehending these factors is essential for fashion marketers seeking to create and

promote products that appeal to culturally varied customers. This section analyses the complex relationship between cultural values and fashion preferences, establishing a basis for investigating how these notions are expressed in Gilgit-Baltistan(14).

Social Norms and Their Role in Fashion Adoption

Social norms profoundly impact fashion adoption, acting as implicit criteria that dictate acceptable behaviors and choices within a community. Social acceptance significantly impacts consumer behavior, as individuals often conform to collective preferences to get favor and maintain their social identity. Community expectations shape fashion trends by fostering ideas of suitability or appeal within a specific cultural or social framework. Such expectations can affect the prevalence of particular styles, often cultivating a sense of belonging among its followers(15,16).

Gender-specific standards complicate matters, as societal norms surrounding masculinity and femininity often dictate suitable attire for men and women. In older communities, norms may restrict fashion choices to culturally acceptable attire, while in more contemporary settings, they may evolve to encompass diverse and unorthodox styles. The interplay between social norms and fashion highlights the imperative for marketers to consider the cultural and social context of their target audience when formulating campaigns or promoting trends. This review analyzes the effect of these dynamics on fashion adoption, offering insights into the impact of cultural norms on consumer behavior in regions such as Gilgit-Baltistan(17,18).

Media and Technology as Drivers of Fashion Awareness

The swift advancement of media and technology has transformed fashion marketing, altering customer interaction with trends and businesses. Digital media has emerged as a pivotal force in fashion awareness, enabling marketers to engage varied audiences via visually engaging and interactive platforms(19). Social media has become a

potent instrument in changing cultural conceptions of fashion, as influencers, content providers, and brands construct trends that appeal to both global and local audiences. These platforms promote immediacy and connectedness, facilitating the spread of trends across cultural boundaries while enabling individuals to express their distinct cultural identities(20).

The amalgamation of e-commerce and digital marketing in culturally diverse areas such as Gilgit-Baltistan presents both challenges and prospects. While internet platforms offer unmatched access to global fashion, they must also account for the unique cultural preferences and sensitivities of the local population. Aligning marketing techniques with local values and practices enhances client trust and engagement(21). Conversely, barriers such as a lack of digital literacy and insufficient infrastructure in rural areas may hinder the adoption of e-commerce solutions. This section critically examines the dual role of media and technology as facilitators of global fashion awareness and as instruments for preserving and promoting local cultural influences in fashion marketing of health-care products(22).

Fashion Marketing in the Context of Local Cultures

Fashion marketing thrives at the intersection of cultural heritage and modern innovation, requiring companies to skillfully navigate the complexities of integrating cultural motifs into their branding strategy. Incorporating local cultural themes, practices, and values into fashion branding allows companies to forge authentic connections with their target audience, fostering loyalty and community involvement. Effective strategies often involve collaboration with local artisans, the use of culturally pertinent patterns or motifs, and tales that highlight the cultural legacy of products(23).

Reconciling traditional values with global changes is a distinct difficulty. Although globalisation has exposed consumers to modern fashion trends, a substantial segment of the population remains firmly anchored in their cultural identities, necessitating marketers to achieve a nuanced equilibrium. This equilibrium can be attained by tailoring global designs to local tastes or endorsing

hybrid forms that amalgamate heritage and modernity(24).

The Unique Cultural Landscape of Gilgit-Baltistan

Gilgit-Baltistan, situated in the northernmost region of Pakistan, exhibits a rich diversity of cultures and ethnicities. The region is home to various ethnic groups, including the Shina, Balti, Wakhi, and Burusho, whose cultural identities are shaped by a blend of languages, traditions, and historical influences. Diversity is seen in traditional attire, which acts as a crucial indicator of heritage, communal identity, and social status. Distinctive clothing styles, such as Balti woolen robes, Shina embroidered headgear, and vibrant Wakhi gowns, represent the region's cultural richness and are functionally suited to its harsh weather circumstances(25).

Nonetheless, the fashion inclinations of Gilgit-Baltistan's populace are transforming due to globalisation, more connections, and exposure to contemporary styles. Younger generations are integrating traditional components with current fashions, producing a distinctive synthesis that embodies cultural pride and modern aspirations. Notwithstanding these alterations, traditional costume continues to be a fundamental aspect of special events, festivals, and communal gatherings, highlighting its lasting significance(26).

Consumer Behavior and the Role of Local Businesses in Fashion Marketing

Cultural factors markedly impact consumer choices in Gilgit-Baltistan, where traditions, morals, and regional aesthetics deeply shape fashion preferences. Religious convictions, familial influences, and community dynamics are essential in purchasing decisions, since they often dictate the appropriateness of trends and the importance of modesty in apparel. Moreover, significant discrepancies exist between urban and rural consumers. Urban areas generally embrace modern trends and brand identity, whilst rural villages remain rooted in traditional attire, reflecting their cultural heritage(27).

Bridging Cultural Heritage and Modern Marketing Strategies

Effectively integrating cultural heritage with contemporary marketing necessitates cooperation between marketers and communities. Co-creation, which incorporates local voices and traditions into product design and marketing strategies, guarantees authenticity and enhances consumer trust. This strategy enables marketers to develop products that align with cultural values while satisfying modern requirements(28).

Narrative is an influential instrument in culturally anchored marketing initiatives. By elucidating the origins, meaning, and workmanship of traditional clothes, marketers may cultivate emotional ties with consumers, thereby enhancing loyalty and pride in local history. Nevertheless, innovation must be judiciously harmonised with cultural sensitivity. Marketers must honour cultural conventions and values while integrating contemporary features, ensuring that new designs or campaigns do not estrange or insult their target. This deliberate amalgamation of culture and innovation facilitates significant and effective marketing techniques(29).

Synthesis of Literature and Gaps

Recent research highlights the substantial influence of culture on fashion marketing, demonstrating how traditions, social norms, and collective values affect consumer behavior and brand strategy. Research demonstrates that incorporating cultural elements into fashion branding enhances authenticity and fosters more robust consumer interactions. Theoretical frameworks such as Hofstede's cultural dimensions and symbolic interactionism have been extensively employed to clarify the connection between cultural identity and fashion choices. Similarly, studies on social media and e-commerce underscore the growing importance of technology in promoting both global trends and localized fashion narratives. Case studies from many nations illustrate the effectiveness of culturally sensitive marketing strategies in enhancing client loyalty and preserving heritage(30).

This study seeks to fill these gaps by offering a detailed comprehension of fashion marketing of

healthcare products within the cultural dynamics of Gilgit-Baltistan. The research provides significant insights for marketers and policymakers by examining consumer behaviour, the function of local businesses, and the amalgamation of legacy with contemporary trends. It also enhances broader discussions on the preservation of cultural identities while promoting innovation in marketing techniques, rendering it an essential contribution to the current body of knowledge(31).

Digitalization and Fashion Marketing

The emergence of digitization has significantly transformed the realm of fashion marketing, affecting customer interaction and brand tactics. Digital platforms, including social media, e-commerce sites, and virtual storefronts, have allowed fashion firms to access broader audiences while offering tailored purchasing experiences. In culturally rich and emerging areas such as Gilgit-Baltistan, where conventional retail infrastructure may be inadequate, digitization has alleviated accessibility disparities by linking local consumers to global fashion trends. Social media influencers, targeted advertising, and algorithmic content curation have profoundly influenced purchasing behaviors, affecting consumer exposure to contemporary and classic fashion styles. The transition to digital commerce has enabled local craftspeople and small-scale fashion enterprises to present culturally significant designs to both national and international markets, promoting economic development while safeguarding history. Nonetheless, digital literacy, internet accessibility, and logistical obstacles persist as significant impediments in the region, affecting the efficacy of digital marketing techniques in reaching varied consumer demographics(32).

The Role of E-Commerce and AI in Fashion Market Expansion

E-commerce platforms, enhanced by breakthroughs in artificial intelligence (AI) and big data analytics, have transformed the fashion marketing of healthcare products through hyper-personalized recommendations and predictive trend research. AI-generated insights allow organizations to customize marketing communications, refine product selections, and improve consumer en-

gements based on behavioral trends. In areas such as Gilgit-Baltistan, where fashion choices are profoundly influenced by cultural traditions, AI-driven recommendation systems can harmonize local aesthetics with emerging global trends, offering tailored ideas that align with consumer values. Moreover, augmented reality (AR) and virtual try-on technologies are revolutionizing the internet shopping experience by alleviating consumer apprehensions regarding fit and style, hence decreasing return rates(33). The incorporation of these technologies in digital fashion marketing of healthcare products not only bolsters customer confidence in online transactions but also enables local firms to distinguish themselves by providing immersive experiences that emphasize the cultural importance of their designs. The use of these advanced digital technologies relies on enhancements in infrastructure and the bolstering of consumer confidence in digital transactions, both of which necessitate strategic development to fully realize the promise of digitalized fashion marketing of healthcare products in the region(34).

Fashion marketing in healthcare products

In the context of Gilgit-Baltistan, cultural identity plays a decisive role in shaping the fashion marketing of healthcare products, where traditional aesthetics are deeply intertwined with social values such as modesty, familial approval, and community representation. Unlike metropolitan markets, where fashion trends may evolve rapidly and are often driven by individual expression, GB consumers tend to make choices influenced by collective cultural frameworks and regional festivals that reaffirm heritage. Local fashion marketing of healthcare products—ranging from health-supportive garments like thermal wear and culturally styled facemasks to functional yet modest apparel—is increasingly reflecting this intersection of tradition and modernity. Research suggests that integrating indigenous design elements and local storytelling into branding strategies not only elevates consumer engagement but also fosters a sense of cultural preservation in the face of globalization. Thus, effective fashion marketing in healthcare contexts must transcend aesthetics and align with the symbolic and ethical codes of the community, reinforcing the idea that cultural congruence is not a constraint but a strategic advantage

in regional markets such as Gilgit-Baltistan.

Methodology

This study utilises a qualitative research approach to examine the cultural impact on fashion marketing of healthcare products in the diversified and culturally affluent region of Gilgit-Baltistan (GB), Pakistan. The approach was meticulously designed to guarantee depth, authenticity, and rigour, conforming to recognised qualitative research criteria(35).

Plan for the Research

Because of its ability to capture the diverse opinions, experiences, and cultural dynamics that influence consumer behaviour and marketing strategies in GB, the qualitative approach was selected as the method of investigation. It is very useful for comprehending complicated social phenomena, where context and cultural complexities play a significant role, and qualitative research is particularly helpful in this regard(36).

A Selection of Samples

In order to pick thirty respondents from a variety of districts in Gilgit-Baltistan, the research project made use of a technique known as purposive sampling. By using this strategy, we were able to ensure that the sample comprised a varied representation of society. This included participants from a variety of age groups, occupations, ethnic groupings, and socio-economic backgrounds. Those respondents who had firsthand knowledge or insight into fashion preferences, cultural norms, and consumer behaviour in the region were the focus of the inclusion criteria(37).

Collecting Numbers

A series of semi-structured in-depth interviews that were semi-structured was used to acquire the data. This structure allows us flexibility in examining the distinct viewpoints of respondents while providing uniformity across important theme areas. In order to promote a rich understanding of the cultural, social, and economic aspects that influence fashion marketing of healthcare products in GB, open-ended questions were used to stimulate thorough replies from survey partici-

pants. The accessibility of respondents was taken into consideration when determining whether interviews were performed in person or through virtual platforms(38).

Study of the Data

The data that were obtained were transcribed and then analysed using theme analysis, which is a method that is widely recognised in qualitative research. Steps such as the following were included in the process:

1. Familiarisation: To get a comprehensive comprehension of the material, the transcriptions were examined on many occasions.

During the coding process, essential phrases, ideas, and concepts were recognised and subsequently converted into codes. We used an inductive approach to construct the codes, which ensured that they arose directly from the data.

3. Classification: Codes that were related to one another were categorised into more general categories and themes.

4. Interpretation: To get insights and comprehend patterns within the data, themes were analysed and interpretations were made.

Throughout the entirety of the research procedure, ethical rules were adhered to in a stringent manner. Through the process of obtaining informed permission from each participant, it was ensured that they were aware of the objectives of the study, the processes involved, and their right to withdraw from the study at any time. All personal identifiers were removed from the data, ensuring that the respondents' anonymity and confidentiality were preserved.

Validity and dependability are both important.

For the purpose of enhancing the validity and reliability of the study, the following strategies were successfully implemented:

- Triangulation: using the purpose of ensuring consistency, the data were cross-verified using the insights of a variety of respondents.

- Member Checking: To ensure that the interpretations of their interviews were accurate, respondents had the opportunity to check them.

- Detailed Description: Accounts of the setting, participants, and conclusions were provided in great detail to enable readers to evaluate the transferability of the study.

When conducting qualitative research in areas with a complex cultural landscape, it is essential to choose approaches that are relevant to the context. The usefulness of purposive sampling for its ability to capture cultural variety and thematic analysis for its ability to extract relevant insights from rich, unstructured data is highlighted by studies conducted in situations that are comparable to those described above. For instance, studies that investigate consumer behaviour in rural and indigenous communities frequently emphasise the relevance of semi-structured interviews, which enable participants to freely interpret their experiences. In addition, the incorporation of cultural viewpoints into the study helps to increase the relevance and applicability of the findings in situations like these.

The approach that was selected is in accordance with the aims of the study since it offers a comprehensive comprehension of the dynamic relationship that exists between cultural heritage and fashion marketing of healthcare products in GB. The study provides nuanced insights into the intricacies of consumer behaviour, the obstacles faced by local businesses, and the prospects for culturally sensitive marketing tactics. These insights are made possible by the study's concentration on qualitative approaches. The results of this study not only fill in the gaps that have been identified in previous research, but they also provide a significant contribution to the field of cultural studies and fashion marketing of healthcare products in general.

Enhancing Data Validation and Thematic Analysis Rigour

To further enhance the rigour of the research process, additional measures were implemented to strengthen data validation and thematic analysis. Thematic analysis followed a structured, multi-stage approach to ensure credibility and consis-

tency. After initial coding, a second round of review was conducted, where codes were reassessed and refined to eliminate redundancy and improve coherence. To validate the emergent themes, peer debriefing sessions were held with qualitative research experts, allowing for external verification of the interpretations. Additionally, inter-coder reliability was established by involving an independent researcher who reviewed a subset of the data to confirm the consistency of the coding framework. This iterative process ensured that themes accurately reflected the underlying patterns in the data, enhancing the trustworthiness of the findings. Furthermore, respondent validation was incorporated, where participants were invited to review preliminary interpretations, ensuring that their perspectives were authentically represented. These rigorous validation techniques reinforce the credibility and reliability of the thematic analysis, thereby strengthening the overall methodological robustness of the study(39).

Data Analysis and Results

The procedures for qualitative data analysis were utilised in order to examine the information that was gathered from the thirty in-depth interviews. The purpose of this study was to provide a comprehensive understanding of the cultural effects on fashion marketing of healthcare products in Gilgit-Baltistan by carefully examining each response and identifying themes and trends. It was decided to produce tables of frequencies to quantify the extent to which particular themes and categories were present throughout the data. It was also decided to construct cumulative results in order to show the overall trends and insights that were provided by the respondents. The analysis made certain that each issue was treated methodically, and that the responses from all thirty participants were taken into consideration in order to arrive at results that were significant(40).

Cultural Values and Fashion Preferences⁵

The analysis of the data, guided by the research question in Table 2, highlights how cultural traditions and values in Gilgit-Baltistan significantly influence clothing and fashion preferences. Tradition and Cultural Identity emerged as the most

dominant themes, each accounting for 23% of responses. These findings underscore the deep-rooted importance of ancestral heritage, family traditions, and pride in cultural identity, which manifest through choices in traditional attire for daily life and special occasions. Modesty (13%) reflects the alignment of fashion with religious and moral values, emphasizing decency and respect. Similarly, Festivals (13%) highlight the role of cultural celebrations, such as weddings and local events, in sustaining traditional fashion practices. Community and Influence, each contributing 10%, showcase the interplay between societal expectations, community values, and modern fashion trends, reflecting a blend of tradition and contemporary influences. Lastly, Work and Daily Attire (7%) illustrates practical considerations, emphasizing comfort and utility in everyday clothing. Overall, the findings demonstrate that fashion in Gilgit-Baltistan is deeply intertwined with cultural values, traditions, and evolving social norms, balancing heritage with modern trends to reflect cultural identity.

Impact of Social Norms on Fashion Trends

The analysis of the thematic main keywords in Table 4 and their classification reveals critical insights into the impact of social norms and community expectations on the adoption of fashion trends in Gilgit-Baltistan. Among the eight identified themes, Modesty emerged as the most prominent, with a frequency of 16.67%, reflecting the significant influence of religious standards, women's modesty, and conservative designs on fashion choices in the region. This highlights how deeply entrenched cultural and religious norms shape preferences, ensuring that clothing aligns with societal expectations of decency and respectability.

Themes such as Cultural Values, Blended Designs, Social Influence, Tradition and Heritage, and Practicality each contributed equally, with frequencies of 13.33%. This demonstrates a balance between adherence to traditional values, the growing acceptance of modern fashion blended with cultural elements, and the practical considerations that inform daily attire and fashion choices. Social influence, driven by peer interactions, social gatherings, and the impact of platforms like social media, underscores the community's role in

⁵ Todas las tablas se publican luego de las referencias.

setting and propagating fashion trends. Similarly, tradition and heritage emphasize the continuity of cultural events and elder guidance in preserving regional fashion identity.

Individuality and Local Preferences, with frequencies of 10% and 6.67%, respectively, reflect a smaller yet significant segment of respondents who prioritize personal expression and localized tastes in fashion. These themes illustrate a nuanced landscape where individuality is increasingly valued amidst collective cultural influences.

Overall, the findings highlight a complex interplay of tradition, social norms, and modernity in shaping fashion trends in Gilgit-Baltistan. The region's unique cultural dynamics ensure that fashion choices remain rooted in its rich heritage while gradually embracing global influences, showcasing a blend of continuity and change driven by community expectations.

Role of Media and Technology in Fashion Awareness

The analysis of the 30 interview responses in Table 6 highlights how media and technology influence fashion preferences and purchasing behaviors in Gilgit-Baltistan, revealing a complex interplay of social norms, cultural values, and modern trends. Social Media Influence emerged as the most prominent theme, accounting for 16.67% of the responses, with key factors such as influencers, celebrity trends, global fashion exposure, and peer sharing shaping consumer decisions. Modern Fashion Trends also held significant weight at 16.67%, with respondents emphasizing the role of modern designs, style updates, and the integration of Western and fusion styles.

Cultural Identity was another important factor, contributing 13.33% of responses, as participants highlighted the tension between cultural pride and local representation versus the global trends promoted by media platforms. Practicality, also at 13.33%, reflected the importance of convenience, accessibility, and rural access in shaping purchasing behaviors, particularly through online shopping.

Themes such as Value-Based Challenges (10%)

and Economic Influence (10%) underscore how fast fashion, price comparisons, and international brands both support and challenge local norms and affordability concerns. While Local and Traditional Brands and Innovation and Experimentation each accounted for 6.67%, they revealed opportunities for preserving cultural traditions through local craftsmanship and customizing modern trends to fit regional preferences.

Overall, the findings underscore the dual role of media and technology as both a driver of modern fashion awareness and a challenge to cultural traditions. Social media, online shopping, and technological advancements have expanded fashion accessibility while introducing influences that sometimes conflict with regional cultural norms. This tension underscores the need for balanced strategies to integrate modernity with cultural preservation, ensuring inclusivity and respect for local identities.

Business Perspectives on Cultural Integration in Marketing

The analysis of responses to the question on cultural integration in fashion marketing of healthcare products in Gilgit-Baltistan reveals six key themes as shown in Table 8. The most significant theme, Cultural Heritage, accounts for 20.00% of the responses, emphasizing the importance of traditional designs, ancestral themes, and cultural sensitivities in aligning fashion campaigns with local expectations. Following closely, Community and Local Involvement and Cultural Pride and Identity each account for 16.67% of the responses. These themes highlight the value of engaging local artisans, fostering community input, and showcasing regional pride and generational balance to resonate with the target audience. Similarly, Marketing Approaches (16.67%) stresses storytelling, visual communication, and cultural education as tools for emotionally connecting with consumers. Ethical and sustainable practices, encompassing modesty and cultural authenticity, also make up 16.67% of the responses, reflecting a growing preference for socially responsible fashion. Lastly, Festivals and Traditions (13.33%) underscore the role of cultural events and traditional patterns in creating timely and meaningful marketing opportunities. Collectively, these findings demonstrate

that integrating cultural heritage, fostering local pride, and maintaining ethical integrity are vital for crafting effective and culturally resonant fashion marketing of healthcare product marketing strategies in Gilgit-Baltistan.

Over all results for influencing factors

The analysis in Table 9 reveals that cultural heritage is the cornerstone of fashion marketing of healthcare products in Gilgit-Baltistan (GB), reflecting the region's deep-rooted traditions and historical identity. A significant proportion of responses emphasize the importance of aligning marketing campaigns with traditional values, ancestral themes, and authentic cultural expressions. This highlights the need for businesses to create strategies that resonate with the local population's pride in their heritage, using storytelling and culturally relevant motifs to forge strong connections.

Modern influences are another critical factor shaping fashion preferences in GB. Social media platforms, online shopping, and exposure to global trends have introduced contemporary aesthetics into the local market. However, this influence does not negate cultural traditions but instead fosters a blending of modern and traditional styles. Consumers are increasingly drawn to fashion that balances modernity with cultural significance, suggesting that businesses should integrate global trends with local motifs in their offerings.

Community and identity also play a pivotal role in shaping fashion marketing of healthcare products in the region. Responses underline the collective nature of fashion preferences, with community alignment, local involvement, and social influences acting as key drivers. Campaigns that foster inclusivity, promote local pride, and celebrate community values are likely to find strong acceptance among consumers.

Practicality and events emerge as influential factors, as traditional attire often serves both functional and cultural purposes. Festivals and local traditions significantly shape consumer behavior, with seasonal and event-specific designs being particularly valued. Marketing strategies that incorporate practical and culturally relevant designs for special occasions can effectively tap into this

segment of the market.

Ethics and modesty are deeply embedded in GB's fashion culture, reflecting the conservative values of the region. Ethical practices such as sustainability, modest design principles, and cultural sensitivity are critical for gaining consumer trust. Businesses that prioritize these aspects can build long-term loyalty and enhance their reputation in the local market.

Economic considerations also influence fashion preferences in GB, with affordability, accessibility, and support for local craftsmanship being crucial. Consumers appreciate brands that offer value while promoting local artisans and products. Additionally, the increasing role of online shopping and customization indicates a shift toward more innovative and convenient purchasing behaviors.

Discussions of Results

The findings of this study underscore the profound impact of cultural heritage and social norms on fashion preferences in Gilgit-Baltistan (GB). Cultural heritage emerged as a cornerstone, shaping both individual and collective fashion choices. The alignment of fashion with traditional values, ancestral themes, and cultural authenticity highlights the population's pride in preserving their identity. This cultural consciousness drives preferences for traditional attire, particularly during special occasions such as festivals and weddings, serving as a visible expression of regional identity. The interplay between tradition and modernity, evidenced by the popularity of blended designs and modern fashion trends, suggests a nuanced acceptance of global influences while maintaining cultural authenticity. Businesses operating in this region must navigate this balance by integrating local motifs with contemporary aesthetics to appeal to both traditional and modern consumer sensibilities.

Modern influences, particularly through media and technology, play a pivotal role in shaping fashion awareness and purchasing behavior in GB. Social media platforms and online shopping have introduced global trends, creating a dual dynamic of modernity and cultural pride. While these platforms challenge traditional norms by introducing

Western styles, they also provide opportunities for promoting local traditions and craftsmanship. The tension between cultural preservation and the adoption of global trends highlights the need for culturally sensitive marketing strategies. For instance, campaigns that use storytelling or emphasize cultural motifs while leveraging digital platforms could bridge the gap between local traditions and contemporary demands, ensuring that fashion remains relevant and accessible to the younger, tech-savvy demographic.

The analysis also revealed the influence of community, ethics, and practicality on fashion trends in GB. Community expectations and social norms significantly shape preferences, with societal approval being a key determinant of acceptable styles. Ethical considerations, such as modesty and sustainability, reflect the region's deeply rooted values and religious principles. The growing importance of practicality, especially in daily attire, and economic factors like affordability and support for local artisans further emphasize the importance of tailoring fashion strategies to local needs. These findings collectively suggest that businesses must adopt a holistic approach, incorporating cultural heritage, ethical practices, and economic accessibility, to create fashion offerings that resonate with GB's diverse and evolving population.

Bridging Tradition and Modernity in Fashion Choices

The findings further reveal that the tension between modernity and tradition is not a rigid divide but a fluid negotiation influenced by generational differences, economic factors, and exposure to global trends. Younger consumers in GB, while valuing their cultural roots, are more inclined to experiment with contemporary styles, often blending traditional elements with modern silhouettes to create hybrid fashion expressions. This adaptation signifies an evolving cultural identity rather than a rejection of tradition. On the other hand, older generations and conservative segments of society advocate for the preservation of authentic attire, viewing external influences as a potential dilution of cultural heritage. This generational contrast indicates a shifting yet coexisting fashion landscape where businesses must strategically position themselves to cater to both audiences. By offering cus-

tomizable designs that allow consumers to incorporate traditional embroidery, patterns, or fabric choices into modern outfits, businesses can bridge the gap between cultural preservation and evolving fashion preferences, ensuring that tradition remains relevant within modern consumer lifestyles.

Theoretical Contribution Enhancement

This study contributes to cross-cultural marketing theory by highlighting how cultural heritage, social norms, and modern influences interact to shape consumer behavior in a unique, culturally rich region like Gilgit-Baltistan. The findings align with the principles of cross-cultural marketing, emphasizing the need for localized branding strategies that integrate traditional values with global trends. By demonstrating how fashion choices are influenced by both deep-rooted cultural identity and exposure to modernity, this study extends theoretical discussions on cultural adaptation in consumer markets, offering insights applicable to other regions experiencing similar cultural transitions.

Conclusion

This study provides a comprehensive understanding of how cultural influences shape fashion preferences and marketing strategies of health care products in Gilgit-Baltistan (GB), highlighting the interplay between tradition, modernity, community, and ethics. Cultural heritage emerges as a dominant factor, with traditional attire and ancestral themes playing a pivotal role in defining fashion choices and reflecting the region's identity. The importance of cultural values underscores the need for businesses to respect and integrate local traditions into their marketing and product design to ensure authenticity and acceptance.

Modern influences, driven by social media and online platforms, reveal a gradual shift towards blending traditional motifs with contemporary aesthetics. This fusion offers opportunities for innovation while maintaining cultural relevance. The growing awareness of global trends does not displace local traditions; rather, it fosters an adaptive and dynamic approach to fashion that integrates the best of both worlds.

Community expectations, ethical considerations, and practical needs further shape the landscape of fashion in GB. Modesty and sustainability are highly valued, reflecting the region's moral and cultural framework. Practicality and affordability also play significant roles in daily fashion choices, indicating the importance of function alongside cultural and aesthetic appeal. Businesses aiming to succeed in this region must adopt a multidimensional strategy that respects cultural values, leverages modern technology, and addresses the economic realities of the local population.

From an academic perspective, this research contributes to the broader discourse on cross-cultural marketing by demonstrating how deeply ingrained cultural traditions influence consumer behavior in emerging markets. It reinforces the importance of culturally adaptive marketing frameworks that balance traditional and contemporary influences. Practically, the findings offer actionable insights for businesses, policymakers, and fashion marketers aiming to develop strategies that resonate with culturally diverse consumer bases. By bridging theoretical understanding with real-world applications, this study provides a foundation for future research on fashion marketing of healthcare products in culturally rich but underexplored regions like GB.

Future resrecah direction and limitation

Future research could extend this study to other regions with similar cultural characteristics to explore the broader applicability of the findings. A comparative analysis between Gilgit-Baltistan and other culturally rich regions would provide deeper insights into the interplay between tradition and modernity in fashion marketing. Additionally, incorporating a quantitative approach, such as surveys or statistical modeling, could complement the qualitative findings by providing empirical validation and measuring the extent of cultural influences on fashion preferences and consumer behavior.

Despite the study's comprehensive approach, certain limitations must be acknowledged. The sample, though diverse, may not fully capture the entire spectrum of fashion preferences across all socio-economic and ethnic groups in Gilgit-Baltistan. Additionally, the reliance on qualitative data, while valuable for in-depth insights, limits the generalizability of findings to broader populations. Future research could incorporate larger and more diverse participant pools, as well as mixed-method approaches, to enhance the robustness and applicability of the results.

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Table 1 Responses for Q N° 1

Respondent	Response	Keyword
1	Our traditional attire, like the woolen shawl, is something I wear for special events. It connects me to our cultural roots.	Traditional
2	For weddings, I wear the Balti dress to represent my culture. It reflects my identity.	Cultural identity
3	I prefer wearing traditional garments like the Shalwar Kameez, as it is a symbol of respect for our traditions.	Tradition
4	On Eid, I wear a local dress that my grandmother wore, keeping the family tradition alive.	Heritage
5	My clothing choices for festivals are always traditional. The colors and styles are important in showing our cultural values.	Festivals
6	I wear modern clothing for work, but for community events, I always wear traditional attire to honor our heritage.	Modern vs. Traditional
7	Our traditional attire, like the embroidered cap, gives me a sense of belonging to my community.	Community
8	During religious ceremonies, I wear modest traditional clothing to show respect to our customs.	Modesty
9	In my daily life, I wear traditional clothes, as they are comfortable and connect me to my family.	Comfort
10	When attending a wedding, I wear a traditional woolen gown. It's a symbol of respect and a way to honor our history.	Respect
11	I always wear a traditional dress on religious occasions to connect with the values of our culture.	Religious values
12	For work, I wear modern clothing, but on holidays, I wear traditional attire to showcase my cultural pride.	Pride
13	My family insists on wearing traditional clothing during festivals, as it's a way of keeping our heritage alive.	Family tradition
14	On special occasions, I wear local fabric dresses because they carry the stories of our ancestors.	Ancestors
15	I like to combine traditional patterns with modern clothing for a unique style that reflects both worlds.	Fusion
16	For me, wearing traditional clothes on Eid is a way of feeling connected to my roots and culture.	Connection
17	Modern fashion trends influence me, but I try to make sure my clothing always reflects my cultural values.	Cultural influence
18	During family gatherings, I wear traditional attire as it shows the respect we have for our ancestors.	Family respect
19	I dress traditionally on religious days to honor our beliefs and to feel connected with my community.	Beliefs
20	I wear modern fashion for work, but when it comes to cultural events, I always choose traditional attire.	Work attire
21	Our culture emphasizes modesty, so I always choose clothing that aligns with those values.	Modesty
22	I enjoy wearing traditional dresses on festivals because they make me feel proud of my heritage.	Pride
23	When attending a wedding, I wear a traditional outfit as it represents my cultural identity.	Wedding
24	I always wear locally made clothes during festivals, as it supports local artisans and reflects our culture.	Local artisans
25	For me, traditional clothing on special occasions is about honoring my ancestors and their way of life.	Ancestral honor
26	Although modern fashion influences me, I never forget to wear cultural attire during important cultural celebrations.	Influence
27	On major religious holidays, I wear traditional attire to preserve the cultural values passed down by my family.	Religious traditions
28	I wear modern clothes day-to-day, but for family events, I prefer traditional dresses to feel connected to our history.	History
29	Our community values traditional attire for special occasions, so I always wear it to maintain that connection.	Community values
30	I wear modern clothing at work, but on cultural days, I always wear traditional attire to honor our customs.	Honor customs

Table 2 Thematic Words classification for Question N° 1

Serial Number	Thematic Main Key Word	Classified Key Words	Respondent Numbers	Frequency	%
1	Tradition	Traditional, Tradition, Heritage, Modern vs. Traditional, Family tradition, Ancestral honor, Religious traditions	1,3,4, 6,13, 25, 27	7	23%
2	Cultural Identity	Cultural identity, Connection, Pride, Respect, Pride, History, Honor customs	2,10, 12,16, 22, 28, 30	7	23%
3	Modesty	Modesty, Religious values, Beliefs, Modesty,	8,11,19, 21	4	13%
4	Community	Community, Family respect, Community values	7, 18, 29	3	10%
5	Influence	Cultural influence, Influence, Fusion,	15,17, 26	3	10%
6	Festivals	Festivals, Local artisans, Ancestors Wedding	5, 14, 23, 24	4	13%
7	Work and Daily Attire	Work attire, Comfort	9,20	2	7%

Table 3 Response for Question N° 2

Respondent Number	Response	Key Word
1	In our community, modest clothing is highly valued and shapes fashion choices.	Modesty
2	We prefer brands that offer traditional designs blended with modern elements.	Blended Designs
3	Social norms in our area discourage overly revealing clothing and promote decency.	Decency
4	I notice that people admire styles that respect cultural values while being trendy.	Cultural Values
5	Within my circle, locally made attire is more acceptable than international brands.	Local Preference
6	Our community prioritizes practicality and comfort over extravagant fashion.	Practicality
7	Fashion trends in our area are heavily influenced by what the elders deem appropriate.	Elders' Influence
8	People in my area admire clothing that aligns with religious and cultural standards.	Religious Standards
9	We often follow styles that are common among friends and family, creating a sense of unity.	Unity
10	Social gatherings are where we observe and adopt acceptable fashion trends.	Social Gatherings
11	I think community expectations create a preference for conservative designs.	Conservative Designs
12	We favor brands that highlight our regional identity and cultural pride.	Regional Identity
13	The youth in our community tend to adopt styles influenced by social media, but only if acceptable locally.	Social Media
14	Modern brands are gaining acceptance, but only those that respect our traditions.	Modern Acceptance
15	I feel pressure to wear styles that are considered modest and appropriate by my peers.	Peer Influence
16	Fashion choices are greatly shaped by family values and communal expectations.	Family Values
17	Popular brands in our region are those that combine elegance with simplicity.	Elegance
18	Our community accepts certain global trends only when they are adapted to fit local customs.	Global Adaptation
19	I believe that social norms encourage us to maintain a balance between tradition and modernity in clothing.	Balance
20	People admire brands that use sustainable and locally sourced materials.	Sustainability
21	In my area, flashy or overly colorful attire is generally frowned upon.	Subtlety
22	We prefer styles that allow us to express individuality without breaking cultural norms.	Individuality
23	Clothing choices for formal events are often influenced by the expectations of influential community members.	Formal Expectations
24	Social norms dictate that clothing for women should be both modest and functional.	Women's Modesty
25	I observe that people in our community are drawn to timeless, classic styles.	Timeless Style
26	Fashion trends here are shaped by a combination of local festivals and religious events.	Cultural Events
27	The acceptance of any new fashion trend depends on how well it aligns with our ethical standards.	Ethical Standards
28	We look up to elders in the community to guide us on what is acceptable in fashion.	Elder Guidance
29	Social norms in our area encourage the use of simple, elegant designs for daily wear.	Simplicity
30	I find that community expectations often limit the adoption of bold or experimental styles.	Limitation

Table 4 Thematic classifications for question 2

Serial Number	Thematic Main Key Word	Classified Key Words	Respondent Numbers	Frequency	Percentage
1	Cultural Values	Cultural Values, Regional Identity, Family Values, Elders' Influence	4, 12, 16, 7	4	13.33%
2	Modesty	Modesty, Religious Standards, Women's Modesty, Subtlety, Conservative Designs	1, 8, 24, 21, 11	5	16.67%
3	Blended Designs	Blended Designs, Balance, Timeless Style, Modern Acceptance	2, 19, 25, 14	4	13.33%
4	Social Influence	Social Media, Peer Influence, Social Gatherings, Formal Expectations	13, 15, 10, 23	4	13.33%
5	Tradition and Heritage	Cultural Events, Unity, Simplicity, Elder Guidance	26, 9, 29, 28	4	13.33%
6	Practicality	Practicality, Sustainability, Limitation, Elegance	6, 20, 30, 17	4	13.33%
7	Individuality	Individuality, Ethical Standards, Global Adaptation	22, 27, 18	3	10%
8	Local Preferences	Local Preference, Decency	5, 3	2	6.67%

Table 5 Responses for Question N° 3:

Respondent Number	Response	Key Word
1	I often use social media to explore new fashion trends and it has influenced my choices significantly.	Social Media
2	Online shopping has made it easier for me to access trendy outfits that were not available locally.	Online Shopping
3	We see many people adopting modern styles seen on social media, but it sometimes clashes with our culture.	Cultural Clash
4	Social media helps us stay updated, but it often promotes styles that do not align with our traditions.	Style Updates

5	I feel local artisans are not represented well on online platforms, which limits cultural influence.	Local Representation
6	Online shopping platforms have given us access to a variety of styles that we could not imagine before.	Accessibility
7	My family prefers traditional attire, but I often find myself drawn to modern designs on Instagram.	Modern Designs
8	We believe that technology is a double-edged sword; it brings awareness but also challenges our values.	Value Challenge
9	Social media influencers have a huge role in shaping what we wear and buy these days.	Influencers
10	Online platforms have made buying clothes more convenient, especially for busy professionals like me.	Convenience
11	I think social media over-represents Western styles, which sometimes overshadow our local traditions.	Western Influence
12	I rely on online reviews before making fashion purchases, which has changed how I shop.	Reviews
13	Platforms like Facebook and Instagram have inspired me to experiment with new looks.	Experimentation
14	I noticed that many people in our area follow celebrities on social media and mimic their styles.	Celebrity Influence
15	Online shopping allows us to compare prices, which has made fashion more affordable for many.	Price Comparison
16	My friends and I often share links to fashion items online, which influences what we choose to buy.	Peer Sharing
17	We feel proud when we see local culture highlighted in online campaigns, but it happens rarely.	Cultural Pride
18	Social media has encouraged me to mix traditional and modern styles for a unique look.	Fusion Styles
19	I find that online ads often promote fast fashion, which is not sustainable for our region.	Fast Fashion
20	Online platforms have made fashion accessible to rural areas, bridging the gap with urban trends.	Rural Access
21	I think people are adopting international brands more due to their heavy online presence.	International Brands
22	We need more local brands to establish their presence online to compete with global platforms.	Local Brands
23	I feel that social media showcases a wide range of fashion options but lacks sensitivity to local norms.	Norm Sensitivity
24	Online influencers often encourage impulsive shopping habits, which is a concern.	Impulsive Shopping
25	My family uses online shopping to buy traditional clothes during festivals, which saves time.	Festival Shopping
26	I have learned a lot about mixing and matching clothes through fashion blogs online.	Styling Tips
27	Social media has made people more aware of global trends, which sometimes conflicts with local norms.	Global Trends
28	I appreciate how some online stores now offer customization to reflect local designs.	Customization
29	Social media campaigns promoting cultural events influence my choice of attire for those occasions.	Event Promotion
30	I feel online shopping discounts have encouraged more people to try out new styles.	Discounts

Table 6 Thematic results for Question N° 3

Serial Number	Thematic Main Key Word	Classified Key Words	Respondent Numbers	Frequency	%
1	Social Media Influence	Social Media, Influencers, Celebrity Influence, Global Trends, Peer Sharing	1, 9, 14, 27, 16	5	16.67 %
2	Online Shopping Impact	Online Shopping, Reviews	2, 12	2	6.67 %
3	Cultural Identity	Cultural Clash, Local Representation, Cultural Pride, Event Promotion	3, 5, 17, 29	4	13.33 %
4	Modern Fashion Trends	Modern Designs, Style Updates, Fusion Styles, Styling Tips, Western Influence	4, 7, 18, 26, 11	5	16.67 %
5	Practicality	Convenience, Accessibility, Rural Access, Impulsive Shopping	10, 6, 20, 24	4	13.33 %
6	Local and Traditional Brands	Local Brands, Festival Shopping	22, 25	2	6.67 %
7	Value-Based Challenges	Value Challenge, Fast Fashion, Norm Sensitivity	8, 19, 23	3	10.00 %
8	Economic Influence	Discounts, Price Comparison, International Brands	30, 15, 21	3	10.00 %
9	Innovation and Experimentation	Experimentation, Customization,	13, 28	2	6.67 %

Table 7 Responses for Question N° 4

Respondent Number	Response	Key Word
1	We believe incorporating traditional designs makes our fashion products more appealing.	Traditional Designs
2	I think promoting cultural festivals helps showcase our local fashion identity.	Festivals
3	Our customers appreciate when we align modern trends with cultural heritage.	Heritage Alignment
4	I have noticed that cultural storytelling enhances the value of our products.	Storytelling
5	We focus on designs that reflect the pride of our regional culture.	Regional Pride
6	I feel our marketing campaigns should emphasize respect for cultural traditions.	Cultural Respect

7	Our business incorporates local artisan work to highlight traditional skills.	Local Artisans
8	We align our branding with community expectations to ensure acceptance.	Community Alignment
9	Our customers prefer traditional patterns for special occasions.	Traditional Patterns
10	I think educating customers about the cultural roots of our products improves sales.	Cultural Education
11	We aim to maintain a balance between modern designs and cultural authenticity.	Cultural Authenticity
12	I have seen that highlighting the region's heritage in campaigns draws more interest.	Heritage Highlighting
13	Our focus on sustainable materials aligns with cultural values of simplicity.	Sustainability
14	We prioritize modest designs to match cultural expectations.	Modesty
15	I believe connecting fashion products to local festivals boosts customer engagement.	Local Festivals
16	We use cultural motifs in our branding to make it relatable to the local audience.	Cultural Motifs
17	Our business involves community input to ensure our designs are culturally appropriate.	Community Input
18	We respect cultural sensitivities by avoiding overly modern styles in our promotions.	Cultural Sensitivities
19	I think promoting locally made products fosters a sense of community pride.	Local Products
20	We integrate ancestral themes into our campaigns to honor cultural traditions.	Ancestral Themes
21	Our customers respond well to campaigns that combine storytelling and visuals.	Visual Storytelling
22	I believe offering customized options reflecting cultural values is vital.	Customization
23	Our team engages with cultural experts to ensure authenticity in our campaigns.	Cultural Expertise
24	I have noticed that incorporating historical symbols appeals to older customers.	Historical Symbols
25	Our advertisements highlight the connection between fashion and local festivals.	Festival Connection
26	We focus on promoting the craftsmanship of local designers in our campaigns.	Local Craftsmanship
27	I feel campaigns must address generational differences in cultural preferences.	Generational Balance
28	We promote our products by linking them to cultural pride and identity.	Cultural Identity
29	Our business thrives by collaborating with local artists to create unique designs.	Local Collaboration
30	I believe emphasizing ethical production methods resonates with local cultural values.	Ethical Practices

Table 8 Thematic frequencies for Q N° 4

Serial Number	Thematic Main Key Word	Classified Key Words	Respondent Numbers	Frequency	Percentage
1	Cultural Heritage	Traditional Designs, Heritage Alignment, Ancestral Themes, Historical Symbols, Heritage, Cultural Sensitivities Highlighting	1, 3, 18, 20, 24, 12	6	20.00%
2	Community and Local Involvement	Local Artisans, Community Alignment, Community Input, Local Collaboration, Local Craftsmanship	7, 8, 17, 29, 26	5	16.67%
3	Cultural Pride and Identity	Regional Pride, Cultural Identity, Cultural Respect, Cultural Motifs, Generational Balance	5, 28, 6, 16, 27	5	16.67%
4	Festivals and Traditions	Festivals, Local Festivals, Festival Connection, Traditional Patterns	2, 15, 25, 9	4	13.33%
5	Marketing Approaches	Storytelling, Visual Storytelling, Cultural Education, Customization, Cultural Expertise	4, 21, 10, 22, 23	5	16.67%
6	Ethical and Sustainable Practices	Sustainability, Modesty, Ethical Practices, Local Products, Cultural Authenticity	11, 13, 14, 30, 19	5	16.67%

Table 9 Consolidated Core Categories with Total Frequencies

Core Category	Thematic Grouped Words (Frequency)	Total Frequency	%
Cultural Heritage	Tradition (7), Cultural Identity (7), Cultural Values (4), Tradition and Heritage (4), Cultural Heritage (6)	28	23.33%
Community and Identity	Community (3), Community and Local Involvement (5), Cultural Pride and Identity (5), Social Influence (4)	17	14.17%
Modesty and Ethics	Modesty (4), Ethical and Sustainable Practices (5), Value-Based Challenges (3), Cultural Sensitivities (3)	15	12.50%
Modern Influence	Influence (3), Blended Designs (4), Modern Fashion Trends (5), Social Media Influence (5), Marketing Approaches (5)	22	18.33%
Practicality and Events	Festivals (4), Practicality (4), Work and Daily Attire (2), Local Preferences (2), Festivals and Traditions (4)	16	13.33%
Economic and Local Impact	Local and Traditional Brands (2), Economic Influence (3), Innovation and Experimentation (2), Online Shopping Impact (2), Local Products (3)	12	10.00%
Festivals and Traditions	Local Festivals (4), Festival Connection (4), Ancestral Themes (2)	10	8.33%

ENHANCING GROUP PSYCHOLOGICAL COUNSELLING THROUGH AI-DRIVEN ETHICAL DIGITALISATION

Jieying Li^{1*}, Pengsen Li²

Abstract: This qualitative study explores the integration of Artificial Intelligence (AI) in group psychological counselling within wellness education through an ethical and interdisciplinary framework. Drawing on 30 in-depth interviews with educators and mental health professionals, the research examines perceptions of ethical digitalisation, the application of knowledge graphs for personalised emotional mapping, the role of outcome-based education (OBE) in structuring measurable psychological goals, and the impact of industry-education collaboration in co-developing AI tools. Thematic analysis identified five overarching domains: ethical governance, data-driven personalisation, outcome alignment, collaborative innovation, and cultural responsiveness. Findings reveal both enthusiasm for AI's potential to enhance support and significant concerns regarding privacy, algorithmic bias, institutional barriers, and the need for human-centred design. The study concludes that effective implementation requires robust ethical frameworks, continuous stakeholder engagement, and adaptive educational structures. These insights offer a conceptual foundation for designing AI-supported counselling systems that align with psychological development goals while safeguarding ethical integrity in diverse educational environments.

Keywords: ethical digitalisation, group psychological counselling, knowledge graphs, outcome-based education, industry education collaboration

Mejora de la terapia psicológica grupal mediante la digitalización ética impulsada por IA

Resumen: Este estudio cualitativo explora la integración de la Inteligencia Artificial (IA) en la terapia psicológica grupal dentro de la educación para el bienestar, desde una perspectiva ética e interdisciplinaria. A partir de 30 entrevistas en profundidad con educadores y profesionales de la salud mental, la investigación examina las percepciones sobre la digitalización ética, la aplicación de grafos de conocimiento para la elaboración de mapas emocionales personalizados, el papel de la educación basada en resultados (EBR) en la estructuración de objetivos psicológicos medibles y el impacto de la colaboración entre la industria y la educación en el codesarrollo de herramientas de IA. El análisis temático identificó cinco dominios principales: gobernanza ética, personalización basada en datos, alineación de resultados, innovación colaborativa y sensibilidad cultural. Los hallazgos revelan tanto el entusiasmo por el potencial de la IA para mejorar el apoyo, como importantes preocupaciones respecto de la privacidad, el sesgo algorítmico, las barreras institucionales y la necesidad de un diseño centrado en el usuario. El estudio concluye que una implementación efectiva requiere marcos éticos sólidos, la participación continua de las partes interesadas y estructuras educativas adaptativas. Estas perspectivas ofrecen una base conceptual para el diseño de sistemas de asesoramiento psicológico con apoyo de IA que se alineen con los objetivos de desarrollo psicológico, salvaguardando la integridad ética en diversos entornos educativos.

Palabras clave: digitalización ética, asesoramiento psicológico grupal, grafos de conocimiento, educación basada en resultados, colaboración entre la industria y la educación

Aprimorando o aconselhamento psicológico em grupo por meio de digitalização ética orientada por IA

Resumo: Esse estudo qualitativo explora a integração de Inteligência Artificial (IA) em aconselhamento psicológico em grupo dentro da educação para o bem estar através de uma estrutura ética e interdisciplinar. Com base em 30 entrevistas aprofundadas com educadores e profissionais de saúde mental, a pesquisa examina percepções sobre digitalização ética, a aplicação de gráficos de conhecimento para mapeamento emocional personalizado, o papel da educação baseada em desfechos (OBE) na estruturação de objetivos psicológicos mensuráveis e o impacto da colaboração entre indústria e educação no desenvolvimento conjunto de ferramentas de IA. Análise temática identificou cinco domínios abrangentes: governança ética, personalização orientada por dados, alinhamento de resultados, inovação colaborativa e sensibilidade cultural. Os achados revelam tanto entusiasmo para o potencial da IA para aprimorar o apoio quanto preocupações significativas com respeito à privacidade, vies algorítmico, barreiras institucionais e a necessidade de um design centrado no ser humano. O estudo conclui que a implementação efetiva requer contexto ético robusto, engajamento contínuo das partes interessadas e estruturas educacionais adaptativas. Esses insights oferecem uma base conceitual para o desenvolvimento de sistemas de aconselhamento apoiados por IA que estejam alinhados com os objetivos de desenvolvimento psicológico, ao mesmo tempo que salvaguardam a integridade ética em diferentes ambientes educacionais.

Palavras chave: digitalização ética, aconselhamento psicológico em grupo, gráficos de conhecimento, educação baseada em desfechos, colaboração entre indústria e educação

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Introduction

The increasing global demand for mental health support has established group psychological therapy as an essential element of wellness education, especially in the education sector(1). The evolving mental health requirements of students, educators, and administrators necessitate the incorporation of modern digital technologies, particularly artificial intelligence (AI), which serves as a potent facilitator of scalable, responsive, and contextually pertinent therapies. The swift implementation of AI-driven solutions prompts substantial ethical concerns related to data protection, consent, algorithmic transparency, cultural sensitivity, and the psychological effects of human-computer interaction(2, 3). Resolving these difficulties necessitates a deliberate and interdisciplinary approach that integrates technical innovation with ethical accountability and educational objectives(4,5).

The research aims to investigate how artificial intelligence can ethically enhance group counselling methodologies while respecting the values and needs of diverse educational groups.

This framework is developed through a qualitative research design utilising in-depth, semi-structured interviews. The research encompassed 30 specialists from China, South Korea, Pakistan, and Iran, chosen by purposive sampling based on their expertise in wellness education, mental health, and educational technology. This varied sample guaranteed cultural and institutional diversity in viewpoints toward AI integration. Participants exhibited variations in data ethics, AI adoption rates, counselor training, and governance structures, enhancing the study's comparative rigor. The data gathering process adhered to rigorous study guidelines established beforehand by the primary investigator, guaranteeing complete compliance with international ethical standards for qualitative research.

The ethical perspective is crucial to this research and was meticulously analyzed throughout the study, especially in relation to wellness education. The ethical dimension encompasses questions of informed consent, digital well-being, equitable access, inclusion, and the appropriate utilisation of AI tools. The study examines the use of ethical

digitalisation in group counselling settings while maintaining the integrity and psychological safety of participants. To uphold the integrity and psychological safety of all participants, we secured informed consent before each interview, explicitly detailing the study's goal, the voluntary nature of participation, and the guarantee of anonymity. Interviews were performed in compliance with institutional ethical norms, ensuring respectfulness, non-invasiveness, and support for participants' emotional well-being.

The suggested framework incorporates knowledge graphs to assist AI in delineating emotional states, social dynamics, and counselling pathways(6). It utilises outcome-based education (OBE) to synchronise counselling techniques with quantifiable objectives for emotional and cognitive development. Moreover, it underscores the necessity of collaboration between industry and education to guarantee that the AI tools created are not just innovative but also practical, scalable, and pertinent to actual educational environments(7).

This study aims to provide a theoretical contribution and practical suggestions for institutions seeking to improve group psychological therapy through ethical, AI-driven digitalisation by utilising interdisciplinary theories and lived experiences. The results are anticipated to guide educational policy, enhance curriculum development in wellness education, and enrich the international dialogue on responsible AI in mental health services.

Research Questions

1. How do educators and mental health professionals within the wellness education sector perceive the ethical implications of integrating AI into group psychological counselling? Focus: *Ethical digitalisation in counselling*
2. In what ways can knowledge graphs be utilised to enhance the effectiveness and personalisation of AI-supported group psychological counselling in wellness education? Focus: *Use of knowledge graphs for AI implementation*
3. How can outcome-based education principles

be embedded into AI-driven group counselling models to support measurable emotional and psychological development among students?
Focus: *Integration of outcome-based education*

4. What are the perceived benefits and challenges of fostering industry-education collaboration in the development and deployment of AI tools for group psychological counselling in wellness education?
Focus: *Role of industry-education collaboration*

Literature review

This literature review aims to investigate and critically assess existing research across several categories pertinent to the ethical digitisation of group psychological counselling in wellness education. The literature review integrates current research from educational psychology, artificial intelligence in mental health technologies, and ethical digital innovation. The aim is to establish a unified framework that connects disparate disciplines, facilitating a comprehensive comprehension of AI's responsible and effective integration into group psychological counselling in educational settings. Some studies emphasise the digital transformation of counselling services, showcasing the advantages of automation, personalisation, and scalability (8). In contrast, others express concerns regarding the dehumanisation of treatment, ethical issues, and the potential for technology reliance. Conversely, studies in wellness education prioritise comprehensive methods for student development, incorporating emotional, cognitive, and social advancement through organised support initiatives (9). Nonetheless, there exists minimal integration between wellness education frameworks and nascent AI applications, particularly in group counselling settings. This review situates itself at the convergence of disparate literatures, seeking to identify deficiencies, compare theoretical perspectives, and provide a cohesive basis for establishing an ethical, AI-enhanced counselling framework specifically designed for the wellness education sector (10).

Group Psychological Counselling in Educational Contexts

Group psychological counselling has emerged as an essential element of wellness education, provi-

ding students with a supportive setting to confront emotional, psychological, and social issues collectively. Research indicates that group counselling fosters a sense of belonging, emotional articulation, and peer affirmation, which are particularly beneficial in educational environments aimed at holistic development (11). Diverse therapeutic models—such as cognitive-behavioural group therapy, humanistic methods, and solution-focused group interventions—have been tailored to accommodate the distinct dynamics of educational institutions (12, 13). These paradigms prioritise contact, empathy, and collective experiences, promoting individual understanding and community unity. Traditional delivery methods frequently encounter obstacles, including a shortage of experienced facilitators, time limits, stigma around help-seeking, and uneven participation. Certain studies suggest that in extensive educational environments, maintaining confidentiality and regulating group dynamics can become complex. These limitations underscore the necessity for creative solutions, such as AI-assisted tools, that can augment established approaches while improving the accessibility, consistency, and scalability of group counselling in wellness education (14).

Artificial Intelligence in Mental Health and Education

The incorporation of artificial intelligence into mental health services has created revolutionary opportunities, especially in psychological counselling. AI solutions, including virtual counselling agents, emotion-recognition systems, predictive analytics, and adaptive learning platforms, have shown promise in enhancing both individual and group counselling processes. In educational environments, AI-assisted therapies are progressively employed to assess student well-being, provide tailored mental health resources, and mimic therapeutic interactions (15). When ethically built and culturally adapted, AI systems can provide scalable psychological support through timely interventions, especially in underprivileged or high-demand educational settings. Recent research indicates that such systems have the potential to enhance access to mental health resources while alleviating the operational burden on human counsellors. Nonetheless, although some studies highlight the advantages of efficiency, scalability,

and data-driven insights, others express considerable apprehension regarding the ethical and emotional ramifications of AI-driven therapy. Risks encompass violations of confidentiality, algorithmic bias, absence of human empathy, and excessive dependence on technology in emotionally complex scenarios. The literature presents a range of viewpoints: some scholars advocate for AI as a beneficial adjunct to human-driven psychological services, highlighting its capacity to improve scalability and personalisation; others warn against its swift deployment without comprehensive ethical, clinical, and contextual assessment. This disparity underscores the necessity for a balanced, interdisciplinary approach to integrating AI into mental health care systems.. These discussions highlight the need for ethically based frameworks that guarantee Wellness education has intricate emotional, psychological, and ethical aspects. Consequently, it necessitates deliberate and contextually aware interventions emphasizing safety, inclusion, and psychological well-being. This requires a careful and evidence-based use of technology, such as AI, in wellness counselling(16, 17).

Ethical Digitalisation in Wellness Education

The ethical digitisation of wellness education has been a pivotal concern as institutions progressively incorporate AI technologies into mental health and counselling services. Central to digital wellness are ethical values like respect for autonomy, data privacy, informed consent, and emotional safety, all of which are crucial when engaging with vulnerable groups such as students in need of psychiatric care. The incorporation of AI into these services presents intricate ethical dilemmas. Research highlights concerns such as algorithmic bias, where AI systems may yield distorted results due to unrepresentative data, and privacy threats arising from the collection and analysis of sensitive psychological data(18, 19).

Moreover, concerns about user autonomy are significant, especially when AI systems begin to influence decision-making in therapeutic contexts. Academics underscore the necessity of culturally sensitive and inclusive digital methodologies, asserting that AI tools should be developed to cater to varied social, emotional, and linguistic contexts to prevent marginalization(20). Despite increasing

awareness, the literature indicates a deficiency in standardised ethical frameworks and institutional norms to direct the responsible application of AI in wellness education. This gap requires the formulation of context-specific ethical principles that address technology accountability while aligning with the values and objectives of wellness-oriented educational settings(21, 22).

Knowledge Graphs in AI and Psychological Applications

Knowledge graphs, as semantic technologies designed to depict structured relationships among concepts, have demonstrated interesting applications in the fields of psychology and behavioral sciences. These AI tools allow machines to comprehend and contextualise human experiences by mapping emotional states, behaviours, and psychological constructs via interconnected data points. In psychological applications, knowledge graphs enhance understanding of mind, emotion, and social dynamics by integrating diverse information sources, such as verbal replies, facial expressions, and digital behaviour, into cohesive semantic networks. Recent research has examined their effectiveness in modelling personal emotional trajectories and group dynamics, particularly in therapeutic settings where comprehension of social influence, empathy, and relational patterns is essential(23, 24).

In group therapy contexts, knowledge graphs can elucidate the relationships among participants' common issues or emotional states, providing counsellors with a real-time, data-informed framework for directing therapies. The application of knowledge graphs, often utilised in medical or informational retrieval systems, to mental health and counselling contexts signifies a groundbreaking multidisciplinary transition. Nonetheless, experts acknowledge problems, including the difficulty of encapsulating nuanced human emotions within rigid semantic frameworks and ensuring the interpretability and transparency of the AI's recommendations. Nevertheless, the capacity of knowledge graphs to enhance psychological modelling and group counselling techniques remains an expanding field of inquiry, particularly within ethically principled educational settings(25, 26).

Outcome-Based Education (OBE) and Its Application in Counselling

Outcome-Based Education is a learner-centred approach that emphasizes the achievement of clearly defined learning outcomes, guiding both instructional strategies and assessment practices. Traditionally utilised in academic and skill-based learning settings, OBE has received increasing scholarly attention over time for its potential to improve educational accountability and learner-centric assessment frameworks. Academics contend that incorporating OBE concepts into group psychological counselling offers a systematic framework for establishing therapeutic objectives, monitoring emotional advancement, and assessing the efficacy of interventions. By pinpointing specific emotional or behavioural outcomes, such as enhanced self-awareness, resilience, or group communication, counselling sessions can be synchronised with overarching educational goals(27, 28).

The utilisation of AI in this context optimises the process by providing tools that assess progress via sentiment analysis, behaviour monitoring, and feedback mechanisms, facilitating real-time modifications to counselling tactics. Some studies commend the integration of OBE and AI-assisted counselling for enhancing responsibility and personalisation, while others warn against oversimplifying intricate emotional development into quantitative measures. Nevertheless, the integration of OBE principles with AI technology presents considerable potential for developing more focused, adaptive, and results-oriented psychological support systems in education(29, 30).

Industry-Education Collaboration in Digital Innovation

Collaboration between industry and education in digital innovation has emerged as a vital catalyst for technical progress in educational and psychological support systems. Diverse collaboration models—spanning strategic partnerships, joint research initiatives, and co-developed platforms—illustrate how educational institutions and the technology sector can work together to tackle complex issues such as digital mental health and the integration of ethical AI. These collaborations

have resulted in the co-creation of AI tools that are both technically sound and rooted in pedagogical and psychological ethics, ensuring conformity with educational principles and student well-being(31).

The success of such collaborations depends on numerous critical variables, including mutual trust, aligned objectives, honest communication, and the incorporation of diversified skills. Research identifies prevalent problems, including misaligned priorities, data governance complications, and power disparities that may obstruct fair development and execution. Despite these challenges, when well managed, such partnerships can yield new, context-specific solutions that improve the digital counselling framework in educational environments while upholding ethical standards and inclusion(32).

Interdisciplinary Frameworks in Education and Technology

Interdisciplinary frameworks that integrate education, psychology, and computer science are crucial for creating holistic solutions in technologically advanced learning and counselling settings. Psychological theories highlight human growth, emotional intelligence, and behavioural modification, whereas educational theory offers learner-centred pedagogy and outcome-based evaluation. Computer science, especially via artificial intelligence, facilitates data-driven decision-making, automation, and adaptive technology(33, 34).

Although current frameworks like socio-technical systems, digital learning ecosystems, and AI-informed educational interventions strive to amalgamate these fields, they frequently fail to encompass the intricate nuances of human emotions, ethical implications, and contextual variability, particularly in the realm of mental health and wellness education(13, 35). Numerous frameworks either rely excessively on technological competencies without adequate psychological foundations or concentrate only on academic results while neglecting emotional health. This highlights a substantial deficiency in the existing literature: an absence of comprehensive, morally grounded, and pragmatically applicable models that effectively synthesise ideas from all three domains (35, 36).

Rectifying this deficiency is essential for promoting AI-enhanced group psychological counselling in wellness education, guaranteeing that forthcoming frameworks are multidisciplinary both in theory and application(37).

Global and Cross-Cultural Perspectives on Wellness and Ethics

Global and cross-cultural perspectives on wellness and ethics reveal significant disparities in the understanding, practice, and institutionalization of psychological well-being and counseling across various nations. In certain areas, wellness education prioritises mindfulness, community support, and holistic development, whilst others implement more clinical, regimented methodologies based on medical or behavioural frameworks. The disparities are additionally manifested in the ethical standards regulating psychiatric therapy, wherein cultural norms influence concepts of privacy, autonomy, emotional expression, and the authority's role in therapeutic partnerships(38, 39).

AI integration in various educational environments may be affected by cultural orientations, such as collectivism and individualism, which shape counseling expectations, privacy standards, and participation behaviors. Collectivist societies often prioritize communal welfare and collaborative decision-making, whereas individualistic cultures emphasize personal autonomy and privacy. These distinctions can influence the perception and utilization of AI-driven counseling solutions(40, 41). This global viewpoint emphasises the necessity for cross-cultural research and policy discussions that connect technical advancement with ethical awareness in wellness education systems(42, 43).

Methodology of the Study

The research utilized a semi-structured qualitative interview methodology with 30 educators and mental health practitioners engaged in wellness education across several institutions. The interview guide included four primary open-ended questions, each designed to investigate a significant thematic area pertinent to the study's interdisciplinary framework: (1) ethical digitalization in AI-assisted counseling, (2) utilization of knowledge graphs, (3) incorporation of outcome-

based education, and (4) collaboration between industry and education.

The questions were intentionally expansive, allowing participants to contemplate, elaborate, and contextualize their answers according to personal experiences, institutional practices, and professional viewpoints. Interviewers employed probing approaches to enhance the exploration of each subject area, frequently leading to discussions lasting 30 to 45 minutes per participant. This method conforms to established qualitative approaches, wherein the depth is attained through the narrative richness and theme saturation rather than solely through the number of structured prompts(44). The research is based on an interpretivist framework that highlights the collaborative creation of meaning between the researcher and the participants(45).

Research Context and Parameters

The research was carried out in many nations, concentrating primarily on organisations and professionals engaged in the wellness education field. Cross-cultural design enhances the comprehension of the interpretation and implementation of ethical AI-driven innovations in group psychological counselling across various educational environments (45, 46).

Participants and Sampling Methodology

Thirty participants were selected using purposive sampling, focusing on persons directly engaged in wellness education and psychological therapy inside educational institutions. Participants comprised counsellors, educators, academic psychologists, digital education professionals, and institutional policy developers. The varied responses gathered from culturally and professionally diverse participants provided a broad understanding of how AI tools are perceived and applied within group psychological counselling across different wellness education contexts.

Method of Data Collection

Data was gathered via semi-structured interviews, facilitating the exploration of specific themes while ensuring consistency among participants

(47). Each interview lasted 45 to 60 minutes and was performed either in person or over secure video conferencing services, contingent upon the participant's location and preference. Interview enquiries centred on participants' experiences with group therapy, perspectives on AI-driven technologies, attitudes towards ethical digitalisation, understanding of multidisciplinary integration, and institutional support systems.

Interview Protocol and (47)s

- An interview guide was developed based on the key thematic areas of the research:
- Role of AI in group counselling processes
- Ethical implications and cultural considerations
- Use of knowledge graphs in psychological modelling
- Outcome-Based Education and Counselling Integration
- Industry-education collaboration. All interviews were recorded (with prior consent) and later transcribed verbatim for thematic analysis.

Data Analysis

Thematic analysis was used to interpret the qualitative data. The analysis followed Braun and Clarke's six-phase approach(48):

- Familiarisation with data
- Generating initial codes
- Searching for themes
- Reviewing themes
- Defining and naming themes
- Producing the report

NVivo software was used to assist with organizing and coding qualitative data. Patterns, themes, and categories were developed inductively to ensure authenticity and coherence with participants' narratives.

Reliability and Precision

Member verification was conducted to establish

trustworthiness, allowing participants to access summaries of their comments for accuracy confirmation. Transferability was preserved by comprehensive descriptions of the environment, participants, and methodologies employed. Dependability was guaranteed via a comprehensive audit trail of all research procedures, while confirmability was addressed through the maintenance of reflective journals to track researcher bias(49).

Ethical Considerations

This research was conducted in accordance with the ethical guidelines governing studies involving human participants. Ethical approval was acquired from a participating university in Pakistan(50).

All participants received an informed consent form detailing the study's objectives, methodologies, potential risks, and their rights, including the option to voluntarily participate and withdraw at any point. Anonymity and confidentiality were strictly maintained through several precautions. All participant data were pseudonymized throughout transcription and analysis, stored on encrypted, password-protected devices, and accessible solely to the core study team. No personally identifying information was documented or revealed at any study phase.

Data Analysis³

Ethical digitalisation in counselling

Table 1 and Table 2 provide a thematic analysis of interview responses regarding how educators and mental health professionals within the wellness education sector perceive the ethical implications of integrating AI into group psychological counselling, with a focus on ethical digitalisation. The most frequently cited theme was Ethical Governance (23.3%), which encompasses concerns around oversight, policy boundaries, institutional guidelines, protocol development, ongoing monitoring, and system alignment. This reflects a strong emphasis on establishing structured and accountable frameworks to manage AI ethically within counseling contexts. A human-centered approach was closely followed, with 20%, highlighting the importance of empathy, human connection, in-

³ Todas las tablas se publican luego de las referencias.

clusion, dialogue, support, and trust in therapeutic environments, as well as the professionals' desire to retain these values alongside technological tools. Privacy and data ethics, as well as algorithmic fairness, were both noted at 13.3%, indicating substantial concern over issues such as data security, consent, confidentiality, transparency, and AI biases—factors that could significantly impact the integrity and equity of digital counseling interventions. Meanwhile, Cultural Sensitivity, Educational Integration, and Critical Reflection each accounted for 10% of the responses, underscoring the need to adapt AI ethically across diverse cultural contexts, integrate interdisciplinary training, and maintain a critical stance toward the limitations and risks of automation. Overall, the data reveal a multi-dimensional awareness among practitioners, with governance and human values emerging as top priorities in ethically navigating AI in group counseling.

Use of knowledge graphs for AI implementation

The analysis of Table 3 and Table 4 reveals that knowledge graphs play a multifaceted role in enhancing AI-supported group psychological counseling within wellness education. The most frequently cited thematic areas—Personalization & Adaptability, Emotional & Behavioral Mapping, Semantic & Contextual Accuracy, AI Decision Support, and Data Structuring & Intelligence—each with a 16.7% share, highlight the core strengths of knowledge graphs in enabling tailored, emotionally intelligent, and data-informed counseling processes. These areas collectively emphasize how knowledge graphs support dynamic, student-specific interventions while maintaining therapeutic coherence and ethical alignment. Slightly less frequent but still important, Group & Peer Interaction (13.3%) reflects the value of understanding interpersonal dynamics, while Cultural Sensitivity (3.3%) suggests an area needing more focus in future applications. Overall, the findings indicate that knowledge graphs are central to creating responsive, ethical, and effective AI-driven counseling environments in wellness education.

Integration of outcome-based education

Tables 5 and 6 provide an insightful analysis of how outcome-based education (OBE) principles

can be integrated into AI-driven group counseling models within the wellness education sector. The thematic word “Goal-Setting & Alignment” (20%) captures the necessity for clear learning outcomes, goal-setting processes, and aligning counseling sessions with the broader educational curriculum to guide the therapeutic process. The “Measurement & Evaluation” theme (20%) highlights the need for concrete, measurable goals, indicators, and performance metrics such as psychological KPIs and rubrics, ensuring that emotional and psychological progress is tracked and evaluated systematically. The theme “Data-Driven Adaptation” (20%) reflects the role of AI in continuously adapting the counseling approach based on real-time data, using progress tracking, analytics, feedback loops, and AI-driven milestones to tailor sessions to individual student needs. Finally, the “Psychological Competency & Development” theme (40%) emphasizes the integration of competencies such as social-emotional learning (SEL) standards, behavioral trends, and holistic emotional development assessment tools, which are critical in fostering overall psychological well-being. The findings underscore the holistic and adaptable nature of AI-supported counseling models, designed to track and enhance student development while aligning with OBE principles.

Interview Responses – Industry-Education Collaboration

The analysis of Table 7 and Table 8 reveals a nuanced understanding of the perceived benefits and challenges of fostering industry-education collaboration in the development and deployment of AI tools for group psychological counselling in wellness education. The most dominant themes, each with a 16.7% frequency, are Strategic Co-Development and Ethical & Privacy Considerations. This indicates that respondents highly value collaborative design, pilot testing, and feedback mechanisms with industry, while also expressing deep concerns over ethical boundaries, data ownership, and the risk of commercialization overpowering student welfare.

Institutional Barriers (13.3%) and Infrastructure & Innovation (13.3%) were highlighted as key challenges, with issues such as unclear policies, communication gaps, and a lack of readiness in

educational institutions to accommodate rapid tech advancements. Educational Alignment (13.3%) also emerged as a vital theme, pointing to the importance of harmonizing technological innovation with curricular relevance and inclusivity. On the opportunity side, Professional Development (10%) reflects how such collaborations can provide mentorship, exposure, and training for educators and counselors.

Less frequently mentioned but still notable were Resource Constraints (6.7%) and Governance & Regulation (6.7%), indicating concerns about funding sustainability and the need for structured oversight frameworks. Cultural Collaboration (3.3%), though least mentioned, highlights an essential aspect—balancing pedagogical values with technological input while ensuring mutual respect.

Final Thematic Grouping into 5 Core Key Words

The final thematic grouping table 9 provides a comprehensive synthesis of insights derived from the study, aligning closely with the research title, “Enhancing Group Psychological Counselling through AI-Driven Ethical Digitalisation: An Interdisciplinary Framework Integrating Knowledge Graphs, Outcome-Based Education, and Industry-Education Collaboration.” The most emphasized theme, AI Intelligence & Data Structuring (30%), reflects participants’ recognition of the need for technically sound AI systems that can deliver contextual accuracy, fairness, predictive insights, and robust data tracking within group counselling. Ethical & Human-Centered Governance (20%) follows closely, highlighting essential concerns around trust, oversight, and data ethics—underscoring that technological advancement must be balanced with human dignity and accountability. Personalization & Psychological Development (20%) emphasizes that AI must enhance emotional support, social-emotional learning, and individualized development, echoing the core objective of psychological counselling. Strategic Collaboration & Institutional Integration (18.3%) brings attention to the enabling role of joint efforts between industry and education sectors, pointing to the infrastructural, cultural, and policy-based mechanisms necessary for sus-

tainable implementation. Lastly, Goal-Oriented Counseling Models (11.7%) reinforce the role of outcome-based education in designing AI tools that align with measurable developmental goals. Collectively, these thematic pillars affirm the need for an ethical, personalized, technically advanced, and collaboratively implemented AI framework for group psychological counselling in wellness education.

Discussions and recommendations

This study’s findings highlight the urgent necessity for creating morally robust, individualized, and cooperative frameworks for incorporating AI into group psychological counselling in wellness education. The rise of fundamental topics such as AI Intelligence and Data Structuring, Ethical and Human-Centered Governance, and Strategic Collaboration indicates the diverse expectations that educators and mental health professionals hold for AI systems. Participants demonstrated robust endorsement for the utilization of knowledge graphs to improve semantic precision and contextual comprehension, facilitating AI in the mapping of emotions and behaviors within dynamic group environments. Moreover, outcome-based education (OBE) has arisen as an effective framework for organizing goal-directed, quantifiable counseling sessions. Nonetheless, apprehensions about prejudice, data exploitation, autonomy, and institutional preparedness suggest that the implementation of AI requires meticulous regulation and ongoing oversight. Collaboration between educational institutions and the technology sector is viewed as both an opportunity and a challenge; successful partnerships can foster innovation, however, also necessitate mutual ethical standards, professional growth, and infrastructural coherence.

This study presents both an empirical exploration and a conceptual framework that advocate for a systematic and interdisciplinary approach to the ethical development of AI tools for group psychological counselling in wellness education, grounded in qualitative insights from international experts. AI systems must incorporate ethical rules, encompassing privacy protections, bias reduction methods, and means for human monitoring. Secondly, knowledge graphs and outcome-oriented educational frameworks must be strategically align-

ned to customize learning trajectories, monitor psychological advancement, and inform intervention strategies. Third, capacity-building initiatives must be institutionalized, emphasizing the training of educators and mental health practitioners in AI literacy and ethical application. Ultimately, the partnership between industry and education must be institutionalized via co-development laboratories, joint governance frameworks, and policy agreements that guarantee AI tools prioritize human-centered objectives over commercial interests. Collectively, these ideas provide a framework for ethically guided, flexible, and results-oriented AI inclusion within the wellness education landscape.

Conclusion

This study emphasizes the revolutionary capacity of AI-driven ethical digitalization in improving group psychological counseling within wellness education. Integrating knowledge graphs, outcome-based education principles, and promoting industry-education collaboration enables the invention of AI solutions that provide individualized, measurable, and ethically sound mental health care. Educators and mental health professionals underscore the significance of ethical governance, emotional intelligence, and interdisciplinary innovation in the evolution of digital counseling. Notwithstanding the excitement surrounding AI's potential, apprehensions over privacy, bias, institutional preparedness, and the threat of dehumanisation linger. The efficacy of AI in psychological counselling relies on both technological progress and a collaborative, morally sound framework that emphasises student welfare, emotional growth, and responsible innovation. This research proposes an exploratory framework informed by thematic insights from international experts, aimed at guiding ethically responsible development of AI-supported group psychological counselling within educational environments.

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Table 1 Ethical digitalisation in counselling

Respondent N°	Interview Response	Keyword
1	I believe ethical oversight is crucial when using AI in any therapeutic setting.	Oversight
2	We are cautious about how AI might unintentionally replace human empathy in group therapy.	Empathy
3	I'm concerned about students' data being misused by AI platforms.	Data Security
4	We ensure transparency in how AI tools process and use participant data.	Transparency
5	I support AI integration, but only with clear ethical boundaries.	Boundaries
6	We struggle with the lack of ethical guidelines tailored for AI in education-based counseling.	Guidelines
7	I find it ethically problematic if students aren't informed how AI evaluates their emotions.	Consent
8	We aim to maintain confidentiality even when digital tools are involved.	Confidentiality
9	I see bias as a serious ethical concern in AI-driven psychological models.	Bias
10	We must be culturally sensitive when developing AI tools for diverse student populations.	Sensitivity
11	I've noticed that some AI systems lack emotional context, which raises ethical red flags.	Context
12	We teach students how AI is used in counseling to foster informed participation.	Awareness
13	I think AI can help, but we must not ignore the human aspect of psychological care.	Humanization
14	We're still exploring how to align AI features with our institutional ethics policies.	Alignment
15	I believe ethical integration starts with training educators and therapists on AI tools.	Training
16	We constantly evaluate the fairness of AI-based group assessments.	Fairness
17	I am skeptical of using AI in areas involving sensitive emotional expression.	Skepticism
18	We believe ethical AI use depends on continuous monitoring and updating of algorithms.	Monitoring
19	I've raised concerns about how AI may reinforce stereotypes in group settings.	Stereotypes
20	We discuss AI ethics with our students to create a shared understanding of its implications.	Dialogue
21	I've seen ethical dilemmas arise when decisions are fully automated without counselor input.	Autonomy
22	We set clear protocols for ethical review before any AI implementation.	Protocols
23	I feel student voices are often missing in ethical decisions about AI use.	Inclusion
24	We are in favor of AI as long as it supports, not replaces, human counselors.	Support
25	I fear AI may desensitize the counseling process if not used carefully.	Desensitization
26	We've established ethical checkpoints during every AI tool deployment in group sessions.	Checkpoints
27	I appreciate the speed of AI but remain concerned about its moral limitations.	Limitations
28	We make sure to include multidisciplinary perspectives when assessing AI ethics.	Multidisciplinarity
29	I think AI brings efficiency, but we must be wary of its impact on student trust.	Trust
30	We follow global ethical standards but tailor them to our student population.	Localization

Table 2 Thematic issues highlight for Q2

Thematic Word	Grouped Keywords	Frequency	
Ethical Governance	Oversight, Boundaries, Guidelines, Protocols, Checkpoints, Monitoring, Alignment	7	23.3%
Privacy & Data Ethics	Data Security, Consent, Confidentiality, Transparency	4	13.3%
Human-Centered Approach	Empathy, Humanization, Inclusion, Dialogue, Support, Trust	6	20.0%
Algorithmic Fairness	Bias, Fairness, Stereotypes, Limitations	4	13.3%
Cultural Sensitivity	Sensitivity, Context, Localization	3	10.0%
Educational Integration	Awareness, Training, Multidisciplinarity	3	10.0%
Critical Reflection	Skepticism, Desensitization, Autonomy	3	10.0%

Table 3 Use of knowledge graphs for AI implementation

Respondent N°	Interview Response	Keyword
1	I use knowledge graphs to link emotional patterns with relevant group interventions.	Emotional Mapping
2	We found that knowledge graphs help personalize therapy sessions by tracking behavioral trends.	Personalization
3	I think knowledge graphs improve the contextual relevance of AI responses during group counseling.	Contextualization
4	We have built semantic maps that connect symptoms to coping strategies in group sessions.	Semantic Linking
5	I rely on structured data from knowledge graphs to understand peer interactions in therapy groups.	Group Dynamics
6	We noticed that knowledge graphs adapt better to individual student wellness profiles.	Adaptability
7	I believe they make AI more intuitive and emotionally intelligent.	Emotional Intelligence
8	We designed a system that predicts emotional needs through linked data in knowledge graphs.	Prediction
9	I use them to identify recurring issues across multiple students in wellness programs.	Pattern Recognition
10	We think knowledge graphs help maintain personalized progress tracking in counseling.	Progress Tracking
11	I see potential in using them to map therapeutic goals and student learning outcomes.	Goal Mapping
12	We've used knowledge graphs to ensure relevance in AI's therapeutic recommendations.	Relevance

13	I integrate them into psychological modeling to enhance response depth.	Modeling
14	We use them to personalize group dialogue based on shared concerns.	Group Dialogue
15	I find their visual nature helps both therapists and students understand emotional pathways.	Visualization
16	We created a student mental health database linked via knowledge graph relations.	Relational Database
17	I applied them to trace behavioral improvements over therapy sessions.	Behavioral Trends
18	We aligned our wellness framework with knowledge-based mental health taxonomy.	Taxonomy Integration
19	I use them to recommend personalized wellness resources.	Resource Mapping
20	We leverage semantic technologies to ensure the AI responses reflect nuanced emotional states.	Semantic Accuracy
21	I like how knowledge graphs help maintain coherence in multi-student counseling scenarios.	Coherence
22	We focus on personalized knowledge links between therapy milestones.	Therapy Milestones
23	I find it easier to design AI responses when graphs show student learning-emotional patterns.	Learning Patterns
24	We connect AI decision paths to ethical models using a knowledge graph backbone.	Ethical Alignment
25	I've used them to prevent repetitive errors in AI responses.	Error Reduction
26	We enhance peer-to-peer support by understanding common behavior nodes.	Peer Behavior
27	I think these graphs help us make emotionally informed decisions.	Emotional Insight
28	We use them to link cultural contexts with therapy relevance.	Cultural Relevance
29	I appreciate their ability to dynamically adapt based on ongoing group input.	Dynamic Adjustment
30	We build evolving therapy models from cumulative graph data.	Evolving Models

Table 4 Thematic frequency and percentage for Q 2

Thematic Word	Grouped Keywords	Frequency	Percentage
Personalization & Adaptability	Personalization, Adaptability, Progress Tracking, Resource Mapping, Dynamic Adjustment	5	16.7%
Emotional & Behavioral Mapping	Emotional Mapping, Emotional Intelligence, Emotional Insight, Behavioral Trends, Learning Patterns	5	16.7%
Semantic & Contextual Accuracy	Semantic Linking, Semantic Accuracy, Contextualization, Relevance, Visualization	5	16.7%
Group & Peer Interaction	Group Dynamics, Group Dialogue, Peer Behavior, Coherence	4	13.3%
AI Decision Support	Prediction, Modeling, Goal Mapping, Therapy Milestones, Ethical Alignment	5	16.7%
Data Structuring & Intelligence	Pattern Recognition, Relational Database, Taxonomy Integration, Error Reduction, Evolving Models	5	16.7%
Cultural Sensitivity	Cultural Relevance	1	3.3%

Table 5 Integration of outcome-based education

Respondent N°	Interview Response	Keyword
1	I use learning outcomes to guide counseling goals and track student progress.	Learning Outcomes
2	We align our emotional support strategies with predefined development objectives.	Alignment
3	I believe measurable goals help personalize group counseling sessions effectively.	Measurable Goals
4	We map counseling themes to specific psychological competencies.	Competencies
5	I structure group activities based on behavioral milestones.	Milestones
6	We assess students' emotional growth using predefined indicators.	Indicators
7	I integrate reflective practices to evaluate both counseling and learning outcomes.	Reflection
8	Our AI tools track psychological progress in line with educational objectives.	Progress Tracking
9	I co-design counseling objectives with students to align with OBE goals.	Co-Design
10	We use AI data analytics to evaluate emotional learning outcomes.	Data Analytics
11	I embed feedback loops to adjust sessions based on emotional outcomes.	Feedback Loops
12	We use outcome-based rubrics to evaluate group counseling impact.	Rubrics
13	I find that goal-setting improves both focus and accountability in counseling.	Goal-Setting
14	Our AI system categorizes interventions based on outcome frameworks.	Intervention Mapping
15	I ensure each session has clear learning goals and psychological objectives.	Session Goals
16	We use emotional assessment tools that match learning outcomes.	Assessment Tools
17	I adapt counseling based on student achievement data from other academic areas.	Adaptation
18	We integrate SEL standards to ensure psychological development is measurable.	SEL Standards
19	I think aligning emotional growth with curriculum objectives improves holistic development.	Holistic Development
20	We continuously evaluate group dynamics in light of educational outcomes.	Group Dynamics
21	I find AI useful in mapping outcome-based behavioral trends.	Behavioral Trends
22	Our feedback system enables iterative improvements in both learning and emotional support.	Iteration
23	I link emotional objectives with cognitive development outcomes.	Cognitive Link
24	We incorporate psychological KPIs to evaluate AI-driven counseling results.	Psychological KPIs
25	I rely on performance metrics to track growth in soft skills.	Performance Metrics
26	We plan counseling curriculum with emotional outcomes as a foundation.	Counseling Curriculum
27	I use digital portfolios to track students' emotional learning journey.	Digital Portfolio

28	We embed milestones within AI algorithms to monitor student development.	AI Milestones
29	I analyze counseling output based on emotional competency rubrics.	Competency Rubrics
30	We co-assess student emotional development alongside academic advisors.	Co-Assessment

Table 6 Thematic words for Q 3

Thematic Word	Grouped Keywords	Frequency	Percentage
Goal-Setting & Alignment	Learning Outcomes, Alignment, Goal-Setting, Counseling Curriculum, Session Goals	6	20.0%
Measurement & Evaluation	Measurable Goals, Indicators, Rubrics, Psychological KPIs, Performance Metrics	6	20.0%
Data-Driven Adaptation	Progress Tracking, Data Analytics, Adaptation, Feedback Loops, AI Milestones	6	20.0%
Psychological Competency & Development	Competencies, SEL Standards, Behavioral Trends, Emotional Assessment Tools,		

Table 7 Interview Responses – Industry-Education Collaboration

Respondent N°	Interview Response	Keyword
1	I think joint ventures with tech firms help bring innovation into our curriculum.	Innovation
2	We sometimes struggle to align industry goals with our educational values.	Alignment
3	I appreciate how tech partners provide access to advanced AI infrastructure.	Infrastructure
4	We find it difficult to maintain long-term commitment from private companies.	Sustainability
5	I've noticed collaboration accelerates the practical application of theories.	Application
6	We need more clarity on shared responsibilities in these partnerships.	Role Definition
7	I value how collaboration boosts our digital literacy and capacity.	Capacity Building
8	We need ethical checks when industries are involved in student-centered tools.	Ethical Standards
9	I think co-developing tools makes the tech more relevant to our actual needs.	Relevance
10	We often face funding constraints that slow down joint innovation.	Funding
11	I've seen faculty resistance when tech dominates the counseling process.	Resistance
12	We collaborate for real-time feedback on pilot AI programs.	Feedback
13	I think students gain more career exposure when companies are part of the system.	Exposure
14	We face data ownership conflicts in cross-sector development projects.	Data Ownership
15	I believe joint development results in tools that reflect educational diversity.	Inclusivity
16	We lack policies that clearly regulate private-sector involvement.	Policy Gaps
17	I support partnerships that involve both pedagogical and technological voices.	Co-Design
18	We are learning how to manage shared timelines and priorities with tech firms.	Coordination
19	I feel industries push for speed while we value ethical deliberation.	Ethical Conflict
20	I believe collaborations must ensure student privacy is protected.	Privacy
21	We need evaluation benchmarks for tools developed collaboratively.	Evaluation
22	I like how partnerships introduce cutting-edge tools in the classroom.	Tools Introduction
23	We should increase training for educators on new AI platforms from companies.	Training
24	I support strategic alliances that lead to long-term innovation.	Strategic Alliance
25	We sometimes face issues in communicating between education and tech language.	Communication Gap
26	I think mentorship programs with companies strengthen student engagement.	Mentorship
27	We collaborate best when both sides have mutual respect and open dialogue.	Collaboration
28	We lack case studies and models for responsible AI collaboration.	Best Practices
29	I fear commercialization may override wellness priorities in some partnerships.	Commercialization
30	We've successfully piloted AI tools with industry support in our group sessions.	

Table 8 Thematic Analysis – Industry-Education Collaboration

Thematic Word	Grouped Keywords	Frequency	Percentage
Strategic Co-Development	Co-Design, Collaboration, Pilot Testing, Application, Feedback	5	16.7%
Ethical & Privacy Considerations	Ethical Conflict, Privacy, Ethical Standards, Commercialization, Data Ownership	5	16.7%
Institutional Barriers	Resistance, Policy Gaps, Communication Gap, Role Definition	4	13.3%
Infrastructure & Innovation	Tools Introduction, Infrastructure, Innovation, Strategic Alliance	4	13.3%
Educational Alignment	Alignment, Relevance, Inclusivity, Evaluation	4	13.3%
Professional Development	Training, Mentorship, Exposure	3	10.0%
Resource Constraints	Funding, Sustainability	2	6.7%
Governance & Regulation	Best Practices, Coordination	2	6.7%
Cultural Collaboration	Respect, Pedagogy-Technology Balance	1	3.3%

Table 9 Final Thematic Grouping into 5 Core Key Words

Core Key Word	Grouped Thematic Words	Frequency	Percentage
1. Ethical & Human-Centered Governance	Ethical Governance, Privacy & Data Ethics, Critical Reflection, Ethical & Privacy Considerations, Governance & Regulation	24	20.0%
2. Personalization & Psychological Development	Human-Centered Approach, Emotional & Behavioral Mapping, Psychological Competency & Development, Group & Peer Interaction, Professional Development	24	20.0%
3. AI Intelligence & Data Structuring	Semantic & Contextual Accuracy, AI Decision Support, Data Structuring & Intelligence, Algorithmic Fairness, Measurement & Evaluation, Data-Driven Adaptation	36	30.0%
4. Strategic Collaboration & Institutional Integration	Strategic Co-Development, Institutional Barriers, Educational Alignment, Educational Integration, Infrastructure & Innovation, Cultural Collaboration	22	18.3%
5. Goal-Oriented Counseling Models	Goal-Setting & Alignment, Resource Constraints, Cultural Sensitivity	14	11.7%
→ Total	—	120	100%

HAVING BREAST CANCER IN THE PANDEMIC: A QUALITATIVE STUDY ON A CASE

Oya Ögenler¹, Selda Okuyaz²

Abstract: Breast cancer is the most common and life-threatening cancer among women. Individual, socioeconomic and cultural characteristics, the society in which she lives, affect the woman's quality of life and health status during the cancer process. The ethical problems women experience due to breast cancer in ordinary times have become more complex with additional problems related to the COVID-19 pandemic. This study aims to raise awareness about the importance of the biopsychosocial approach in the physician-patient relationship through the experiences of a case diagnosed with breast cancer. Our study evaluated and compared the experiences and opinions of a 52-year-old woman diagnosed with invasive ductal breast cancer in the first six months of the epidemic with the literature. It is clear that breast cancer is closely linked to sexual identity, and "being a cancer patient" can be described as a life-changing crisis. The pandemic period has characteristics against the cancer patient due to restrictions. She stated that the patient diagnosed with cancer had positive characteristics, such as a physician-patient relationship and social determinants in the hospital-related processes, but she experienced social exclusion due to the pandemic period. As a result, it is clear that the biopsychosocial holistic view of the health personnel is as effective as the patient's individual characteristics and social determinants, the relationship between the patient and the health personnel, and the shaping of the treatment process.

Keywords: breast cancer, physician-patient relationship, COVID-19, ethical issues, quality of life

Cáncer de mama en la pandemia: un estudio cualitativo sobre un caso

Resumen: El cáncer de mama es el cáncer más común y potencialmente mortal en mujeres. Las características individuales, socioeconómicas y culturales, así como la sociedad en la que viven, afectan su calidad de vida y su estado de salud durante el proceso oncológico. Los problemas éticos que las mujeres experimentan debido al cáncer de mama en tiempos normales se han vuelto más complejos junto con los problemas adicionales relacionados con la pandemia de COVID-19. Este estudio tiene como objetivo concientizar sobre la importancia del enfoque biopsicosocial en la relación médico-paciente, a través de las experiencias de un caso diagnosticado con cáncer de mama. Nuestro estudio evaluó y comparó las experiencias y opiniones de una mujer de 52 años diagnosticada con cáncer de mama ductal invasivo durante los primeros seis meses de la epidemia con la literatura existente. Está claro que el cáncer de mama está estrechamente vinculado a la identidad sexual, y ser "paciente con cáncer" puede describirse como una crisis que cambia la vida. El período de la pandemia presenta características adversas para los pacientes con cáncer debido a las restricciones que se presentan. La paciente afirmó que tenía características positivas, como una buena relación médico-paciente y determinantes sociales en los procesos hospitalarios, pero experimentó exclusión social debido al período de la pandemia. Como resultado, es evidente que la visión holística biopsicosocial del personal sanitario es tan eficaz como las características individuales del paciente, los determinantes sociales, la relación entre el paciente y el personal sanitario y la configuración del proceso de tratamiento.

Palabras clave: cáncer de mama, relación médico-paciente, COVID-19, cuestiones éticas, calidad de vida

Tendo câncer de mama na pandemia: um estudo qualitativo de um caso

Resumo: Câncer de mama é o câncer mais comum e ameaçador à vida entre mulheres. Características individuais, sócio-econômicas e culturais e a sociedade na qual ela vive, afetam a qualidade de vida e o estado de saúde da mulher durante o processo do câncer. Os problemas éticos que as mulheres vivenciam devido ao câncer de mama em tempos normais, tornaram-se mais complexos com problemas adicionais relacionados à pandemia pelo COVID-19. Esse estudo objetiva aumentar a conscientização sobre a importância da abordagem biopsicosocial na relação médico-paciente, através das experiências de um caso diagnosticado com câncer de mama. Nosso estudo avaliou e comparou experiências e opiniões de uma mulher de 52 anos de idade diagnosticada com câncer de mama ductal invasivo nos primeiros seis meses da epidemia com a literatura. Está claro que câncer de mama está intimamente ligado a identidade sexual e "ser um paciente com câncer" pode ser descrito como uma crise que muda a vida. O período da pandemia tem características desfavoráveis para paciente com câncer devidos às restrições. Ela afirmou que a paciente diagnosticada com câncer tinha características positivas, tais como a relação médico-paciente e os determinantes sociais nos processos relacionados ao hospital, mas ela vivenciou exclusão social devido ao período da pandemia. Como resultado, está claro que a visão holística biopsicosocial do pessoal de saúde é tão eficaz quanto as características individuais do paciente e os determinantes sociais, a relação entre o paciente e o pessoal de saúde, e a definição do processo de tratamento.

Palavras chave: câncer de mama, relação médico-paciente, COVID-19, questões éticas, qualidade de vida

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Introduction

The coronavirus disease 2019 (COVID-19), identified in December 2019 in Wuhan, China, was declared a global epidemic by the World Health Organization (WHO) in early March 2020. As in many other countries, regulations have been made for health care services as of March 10, 2020, in Turkey(1). In this period, individuals with chronic health problems, including cancer patients, were more adversely affected than standard patients. The absence of cancer-specific emergency standards other than the standards of care for the COVID-19 pandemic, such as justice, the duty of care, the duty to protect resources, transparency, consistency, proportionality and accountability, caused the process to change against the individual with cancer. Restrictions on diagnosing and treating cancer diseases and elective surgeries can be classified as the most significant disadvantages during the pandemic(2). However, in ordinary times, cancer is a physical and psycho-social disease that includes many surgical processes, the excess of drugs used and their side effects, the possibility of metastasis, body image loss anxiety, economic, psychological, emotional, physical and environmental difficulties. There are differences in cancer rates according to gender. The impact of COVID-19 on cancer patients during the pandemic also differed by gender and age(2,3,4). Cancer treatment cannot be postponed for any event, as in oncology, studies show that patients with low immunity is more affected by the COVID-19 disease, affecting the mortality rate, is not considered safe enough to prevent treatment. The cancer patient is a member of a vulnerable group(2). In the COVID-19 pandemic, the magnitude of the effects of suspending screening programs for cancer patients, the closure of standard polyclinic examinations in the health system, and delays in cancer diagnosis and treatment on diagnosis and mortality rates cannot be estimated. While delays in diagnosis and barriers to transportation cause a decrease in incidence, barriers to access to cancer treatment and care are likely to cause an increase in advanced-stage diagnoses and cancer deaths(2,5,6).

Breast cancer, the most common among women, accounts for 25% of all female cancers worldwide(7). In general, the increase in cancer patients

worldwide and in Turkey can be attributed to living conditions such as unhealthy diet, alcohol and tobacco use. The estimated number of new cancer cases worldwide in 2020 is 19.3 million, with 233,834 in Turkey(3,7). Female breast cancer ranks first in new cancer cases, followed by lung, colorectal, prostate and stomach cancers. Cancer is one of the most important causes of death under the age of 70 in many countries, including Turkey(7).

Cancer is a chronic systemic disease(8). Being diagnosed with a chronic disease can turn the lives of patients and their families upside down. Everything from daily routines to family dynamics has to change to adapt to the new normal the disease brings. In addition to the economic and cultural difficulties in the chronic disease process, the possibilities and life expectancies of the patient are effective in coping with the difficulties. The disease, which disrupts the general functioning of the patient's environment, can lead to biopsychosocial problems, and the patient and her family may not know how to cope with difficulties during the process. Family members may face different emotional challenges depending on their relationship with the loved one who has the disease. The patient may feel grief or loss about her life and the future she imagined before her diagnosis. The family member who cares for the patient may sometimes feel overwhelmed and exhausted and experience compassion fatigue. The effect of the disease on the patient and her environment can be more complex and challenging due to the intensity of the side effects of the treatment process in cancer(9).

In addition, it can be thought that the fear of death of cancer patients and their relatives may differ from other times during the pandemic. The mentality of the health personnel who provide health care for cancer in the event of a pandemic or a possible disaster can determine the attitude and behavior of the cancer patient undergoing the diagnosis and treatment of cancer. Some recommendations draw an ethical framework for the treatment of individuals with cancer in resource-limited settings. Unfortunately, these inconsistent frameworks cannot be said to meet the required need(2). Very recently, an earthquake in Turkey affected 11 provinces and, indirectly, the whole country. The cancer patient underwent the process

in an intense period, except for her disease. Natural events, terrorism, and war will affect the cancer patient more than the normal individual.

For this reason, it is important to examine the sample cases reached in extraordinary periods to shape the diagnosis and treatment processes in favor of the patient. In this context, the views of a patient diagnosed with early-stage cancer during the pandemic period in 2020 were evaluated in comparison with the literature in terms of biopsychosociality. This study aims to guide the patient-healthcare worker relationship and raise awareness by evaluating the approach to the body and death of the patient diagnosed with cancer in extraordinary situations such as pandemics from a biopsychosocial perspective.

Case

Right breast-conserving surgery was performed on a 52-year-old single and nulliparous patient diagnosed with invasive cancer with a tru-cut biopsy in November 2020. Axillary node was negative, stage 1 right breast cancer (T1, N0, M0), HERS2-, and Ki-67<10 hormone receptors were positive. The patient, a healthcare worker, received four cycles of chemotherapy and 35 working days of radiotherapy after surgery. She was scheduled to take 1 mg of anastrozole for ten years. She is still being followed up by the general surgery and medical oncology departments every six months.

Discussion

The number of patients diagnosed with cancer through screening programs is increasing day by day. The difference of 75% between the number of patients diagnosed between 2008 and 2020 can be considered an indicator of the rate of increase(10) 30% of cancer diagnoses in women are breast cancer, and 15% of deaths are from breast cancer. However, with the help of cancer screening programs, early diagnosis and treatment opportunities have reduced the expected death rates from cancer(11). There are 331 Cancer Early Diagnosis, Screening and Education Centers (KETEM) in Turkey, at least one in each province(10). It is envisaged that women apply to KETEM or different cancer diagnosis centers at the secondary and tertiary levels in an organized manner. Breast

cancer is followed up with monthly breast self-examination and once-a-year mammography, recommended for all women between the ages of 40 and 69(12).

Our case had a regular ultrasound every six months for five years before diagnosis due to axillary lymphadenopathy, and had a mammogram once a year. When she applied to a different health institution two months later than usual, instead of the sixth month due to the pandemic, for the USG before the diagnosis, the radiologist who performed the USG stated that he saw a suspicious mass, but added that three months could be waited for the biopsy. Since the patient is a healthcare worker, it can be thought that she is less affected by this process, which works against the cancer patient. The fact that a woman tries so hard for early diagnosis of breast cancer with the thought that 'I can be sick at any moment' is a great haste to delay the disease and protect the body. According to this view, a woman should do everything she can, knowing it is her responsibility. The literature supports the efforts of our case for early diagnosis. Following the traditional sexist role, the woman passively and patiently strives for her body, which needs to be exhibited and protected, knowing that cancer can happen at any moment. For a woman who sees herself through someone else's eyes, protecting her health can be synonymous with protecting her body. From this point of view, a breast cancer diagnosis can be a tool for protecting the body, not a goal. The difference of the breast from other organs is that it is important in cosmetics and body image and is accepted that it represents gender. The female breast is in an important position for the woman in the visible part of the body, which has pleasant curves and enables the baby to integrate with the mother. According to the value given by society, the breast, which must be alive enough to defy gravity, is complemented by clothing and contributes to the sexual appearance of the woman(13,14). It is certain that the influence of society's health discourses on the formation of the thoughts of women with cancer, including our case.

Cancer treatment process

According to the WHO definition, health is not only physical but also mental and social well-be-

ing. Physiological and biological markers of the health of the patient diagnosed with breast cancer include imaging tests such as breast MRI, PET scan, blood biochemistry, immunological and histopathological diagnosis methods, and many procedures performed on the patient or tissue before and after surgery. It can be argued that the mental state of a woman diagnosed with breast cancer differs from that of other disease diagnoses(15,16).

The coordinated work of radiology, surgery, pathology, medical oncology and radiation oncology in cancer processes will shape the patient's future. Physicians need information about the woman's life expectancy, social and mental state, and body in terms of clarification and consent. The patient and her relatives are in the process psychologically, socio-culturally and economically. How long the treatment process will last, how much it will affect the patient and her environment, and possible negativities are critical situations that should be understood in detail by the patient and her environment.

The patient's emotional state, physical health, quality of life and treatment compliance will vary according to the approach of the physicians/health personnel. The woman's body image will change depending on the type of surgery determined by the general surgeon according to the stage and type of cancer. The woman's lived experiences, beliefs, and body perception, depending on the thoughts of others about her own body affect the psychological and physiological state in the post-operative period(17). The surgeon's clarification will prevent the patient's anxiety about her illness and body image. Even if the physician's knowledge and experience, as well as the patient's adequacy, do not eliminate the body image anxiety, it enables the patient to act by believing that the decision made is correct for the patient's future. The patient may not change the decision made by the physician, and the possibility of rejection may be very low, but the clarification of why the operation was performed in this way will enable the woman to say "the right decision" in the absence of beautiful curves while wearing her dress every day(18). The importance of realistic information given by the physician, allowing questions to the physician, and a confident and supportive healthcare professional cannot be denied.

Possible problems, side effects, and survival should be explained to the patient. However, as mentioned in one study, it is wrong to set a deadline for your life by a physician. Giving percentages of how much life is left causes people to become numbers. The surgeon of our case mentioned that the cancer was detected at an early stage, that the operation would be shaped according to the axillary metastasis during the operation, and that possible side effects were mentioned, but no explanation was given that the date of death would affect the prognosis. In case of complete closure during the pandemic, the procedures have been accelerated to perform the surgery as soon as possible. The physician's asking the patient what information she wants to learn will contribute to the patient's compliance. Confidence and compliance with treatment will increase when the patient receives information about the prognosis, similarly from all physicians participating in the process from the beginning of the disease(19). The chemotherapy process was followed by a medical oncologist in a different city instead of the patient's health institution. The possible percentages of metastases after treatment were mentioned in the clarification and consent of the medical oncologist. The chemotherapy drugs to be chosen, the purpose for which they are chosen and their contribution to the treatment of the patient are explained. The side effects of the drugs used in each chemotherapy cycle were explained to the patient in detail, and the possible side effects and the drugs to be used and the emergency numbers to call were given to the patient with a written document. The patient who had a throat infection during the second chemotherapy cycle stated that when she heard the sentence "do not be in the hospital, there is no place for you" from her physician friend in the city where she lived, she felt that she could die at that moment. The sentence "There is no room for you" is a cautionary example of how the restrictions affect the cancer patient's chances of survival, with no chance of being hospitalized with an illness other than COVID-19 during the pandemic. Cancer is associated with "death" in society. A study stated that healthcare professionals informed their patients about the prognosis based on mortality(19). In our case, there was no association with death in the clarification process. The healthcare professional friends outside the pa-

tient's immediate family associated the diagnosis with death and exposed her to social stigma/exclusion. In the literature, there is a need for a study on the views of healthcare professionals about the social exclusion/stigmatization of cancer patients or their relatives.

Being diagnosed with cancer, the presence of metastases, and how the treatment process will be shaped affect the patient and her family. Socio-economic opportunities, insurance availability, accessibility to the physician, and difficulties in understanding the terminology in the diagnosis and treatment of cancer necessitate mentioning the existence of a socio-cultural emotional dimension that is more intense and different from other diseases(16,20,21). In this context, the social determinants of health can be divided into five subgroups; individual (age and gender), socioeconomic (unemployment, working conditions, poverty and social exclusion), environmental (housing, social environment and clean food and water), lifestyle (physical activity, addiction and sexual preferences) and transportation (transport, social services, education). Our case stated that her characteristics are being over 50 years old and in menopause; socioeconomically, she has above-average economic power as an active health personnel and sufficient social support for the hospital process. However, she has experienced social exclusion due to the pandemic and her cancer. As environmental determinants, living in a house with clean water and positive features in terms of the environment; as lifestyle, she stated that she had a history of smoking for four years, did not have any addiction history and was not married. She added that since it was a pandemic period, a permit was obtained to be used in all restrictions for transportation and social services, and she used her means. Our case has positive characteristics in terms of social determinants that many women with breast cancer do not have. According to studies, the patient's quality of life and health are adversely affected by the negativity of social determinants. There are also studies showing that women have worse health status in terms of social determinants(20). The health status of economically weak people is defined as worse. It is important for our case to be in good financial condition, have easy access to hospital facilities from a social point of view,

and be able to meet her health-related needs with her means, especially in a period when chronic patients are having problems, such as during the pandemic period. However, it is important, mentally and socially, that she states that she is deprived of the communication network provided by others as social support, which makes the individual feel cared for and loved, and that she is experiencing social exclusion(20). Breast cancer is a disease directly related to the sexual identity of women. Our patient stated that she could not tell non-health individuals she had breast cancer because the word "breast" had sexual connotations.

With the cancer diagnosis, the person has encountered a traumatic event that threatens her existence and changes her normal life, making her think she will die. Being diagnosed with cancer is a situation suitable for the definition of "crisis"(16). If we or someone close to us is experiencing a loss, a unique experience occurs, respectively, which is overwhelming and confusing; it is suggested that during this period, the patient will experience five phases of emotions, such as denial, anger, bargaining, depression and acceptance, according to Kubler-Ross classification(22). At the same time, the patient, who is in a physically, psychologically, socially, economically challenging period for diagnosis and treatment, experiences a period of "crisis" regarding her health(15). Studies are showing that the psychological state of women diagnosed with cancer affects the acceptance of the disease and compliance with the treatment process. The abilities and experiences of the patient diagnosed with cancer will affect her coping with the crisis(16). The insidiousness and fatality of cancer, the changes in the body during the treatment process, and the process of becoming ugly and in need of care provide the emotional definition of the process. According to the literature, women with cancer who experience anxiety after diagnosis experience more distress, anxiety and depression than men(16,21). Since our case is a health worker, it can be argued that the level of knowledge on cancer and death contributes to the excellent management of the process, and as a health worker, the physician-patient relationship is different from non-health patients. The positive features of the patient's treatment compliance process may have reduced the discomfort caused by the treatment.

The patient with a cancer diagnosis requires a medical understanding beyond the standard medical approach, with good communication skills and far from stereotypical thoughts, more than the patient diagnosed with any disease. Communication between the physician and the patient will create trust and ensure that the patient's health is positively affected(23). As seen in our case, the positive effect of the physician-patient relationship is obvious. Attitudes and behaviors of patients, physicians and their environment towards "goodness" shape the disease process of women with breast cancer(20).

Conclusion

It is important to ensure the institutional structure that will ensure the continuity of the approach in the diagnosis and treatment process in the ordinary period so that the patient does not suffer from inequality due to restrictions during the pandemic. The case stated that although she was a healthcare worker, she was affected by limitations and social exclusion. It should be considered that cancer is a disease that is affected more by social

determinants than other diseases for each period. For this reason, it is important to determine the presence of the patient's biological markers and other factors and to support them with social institutions for the disease process to be positive, increase the quality of life, and be healthier. It is important to inform the diagnosed patient and their family about what will happen during the disease process, including biological, psychological, and social factors.

The biopsychosocial approach to the cancer patient will affect the entire treatment process from diagnosis. Since cancer is a disease that requires multidisciplinary work in the diagnosis and treatment process, opening multidisciplinary areas that will ensure this unity in hospitals, providing physicians and all healthcare professionals with the necessary training to provide the biopsychosocial approach necessary for cancer patients, to reveal the positive and negative attitudes and behaviors that will affect the patient-physician relationship administratively and to provide the necessary initiatives to reinforce the positive features and eliminate the negative features are important.

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WORLD HEALTH ORGANIZATION***From loneliness to social connection - charting a path to healthier societies: report of the WHO Commission on Social Connection.***

Geneva: World Health Organization; 2025. Licence: CC BY-NC-SA 3.0 IGO. ISBN 978-92-4-011236-0 (electronic version) ISBN 978-92-4-011237-7 (print version)

Fernando Lolas Stepke¹

El concepto de “salud social” es, como dice este reciente informe de OMS, el “tercer pilar” del concepto de “salud” propugnado por esa organización, cuya clásica definición indica que salud es un completo estado de bienestar físico, mental, espiritual y social y no solamente la ausencia de enfermedad.

Aunque esta definición es utópica, pues nunca existe completo bienestar y las personas “sanas” o “normales” viven en realidad en una zona “neutral”, con estados variables de bienestar y malestar, lo importante es el desglose analítico de esta nueva propuesta. La mayoría de las definiciones de salud se refiere a individuos y por ello su expansión a áreas tales como *salud global*, *salud pública* y *salud internacional* encuentra dificultades para dar cuenta de los “determinantes relacionales” del estado de bienestar. Estos no siempre son controlables por los individuos, porque dependen de interacciones con otras personas. No siempre las expectativas individuales encuentran eco en el comportamiento de éstas, como se evidencia en el discurso sobre derechos que carece por completo de significado o concreción real si otras personas no sienten como deber respetarlos. Un derecho subjetivo, aunque se manifieste en códigos escritos, es siempre necesidad o deseo legitimados en un contexto específico y su frecuente desconocimiento o violación dependen de los contextos en que se proclaman. La influencia de la cultura y las determinaciones económicas o políticas explican que lo que es derecho en algunas partes del mundo o para algunos grupos no sea plenamente reconocido o aceptado universalmente.

Autonomía, individualidad y conexión son indisociables de la vida contemporánea. Difíciles de articular armoniosamente en la vida cotidiana, porque existen “estilos individuales” codificados bajo el término técnico “personalidad”, que alude a la construcción individual de los hábitos y a preferencias que se manifiestan en muchos ámbitos vitales. Conocido es que tales características individuales predisponen a algunas personas a trabajar y vivir mejor rodeadas de otras personas, y a otras a preferir el aislamiento. Incluso, hay variaciones circadianas en la forma que cada individuo responde a las solicitudes de la vida social e incluso a los efectos de algunos estimulantes. La cafeína puede mejorar el rendimiento intelectual en algunos, pero puede reducirlo en otros.

La diversidad humana es una constante que necesariamente debe ignorarse cuando se planean intervenciones societarias o se formulan políticas públicas. La acción de los psicofármacos depende no solamente de las expectativas que se pongan en ellos sino también de características de los sistemas nerviosos. Ivan Petrovich Pavlov pudo distinguir entre perros con sistema nervioso fuerte y perros con sistema nervioso débil cuando comprobó que no todos reaccionaban igual ante situaciones estresantes. Muchas generalizaciones basadas en estereotipos prueban ser incorrectas, como aquellas que se refieren a grupos etarios. Precisamente, en la ancianidad (como nos recuerda Jonathan Swift en su sátira sobre los Struldbruggs) es cuando más difieren entre sí las personas, de modo que hablar de “la tercera edad” como un grupo homogéneo entraña desconocer que la diversidad humana es la regla. Debiera tenerse

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en cuenta en generalizaciones sobre el efecto de las intervenciones sobre la salud y el sistema nervioso antes de declarar precipitadamente que algunas son beneficiosas y otras deletéreas. Tal vez esto constituya una buena base para reflexionar sobre el futuro de las máquinas humanoides y sin duda tiene implicaciones cuando se trata con especies no humanas. Los animales también tienen “personalidad” (el clásico libro de Munro Fox lleva ese título).

Tres conclusiones cruciales emanan de este informe. La primera es que la soledad no deseada, entendida como aislamiento y falta de contactos de apoyo en situaciones de emergencia, tiene consecuencias negativas y afecta al bienestar de las personas.

La segunda es que impacta en la salud percibida y en la salud objetiva de las personas de modo negativo, incrementando la morbilidad y la mortalidad.

La tercera es que la acción mancomunada de los expertos y las personas que toman decisiones en salud pública puede contribuir a diseñar intervenciones que propicien la conexión social.

La existencia de ministerios de la soledad, como los existentes en Gran Bretaña y Japón, indica la importancia que se ha dado al problema de la falta de conexión social. Sin embargo, cabe recordar que las intervenciones deben ser adecuadas al contexto social y científico en que se implementen. No todas las conexiones sociales son positivas. Algunas pueden no ser beneficiosas. Las personas, por su diversidad, pueden preferir algunas y rechazar otras.

Hay que distinguir, por tanto, entre los sentimientos subjetivos de soledad que pueden experimentarse incluso en una multitud y el aislamiento no deseado, producto de limitaciones físicas, vejez o enfermedad (*La multitud silenciosa*, de Riesman y colaboradores, puso este tema en boga en los años 50 del siglo XX, aunque el título no responde exactamente a la intención de los autores). Cualquier intervención debe estar precedida por un análisis sociológico del tipo de comunidad al que se pertenece, pues en algunas culturas priman cánones de sociabilidad que no pueden generalizarse. Cuando se habló de “sociedades enfermas” (Halliday) todo el mundo académico entendió que se trataba de una metáfora, porque la sociedad no es un “sujeto” que pueda enfermar. No obstante ello, puede emplearse esta expresión para situaciones de anomia generalizada, caos destructivo y prevalencia incrementada de dolencias personales.

Este informe, profusamente ilustrado con datos y estudios, es sin duda un valioso aporte a la comprensión de estos fenómenos —aislamiento, soledad, conexión social—, a su estimación cuantitativa y su evaluación cualitativa, y a sus implicaciones sanitarias. Es un significativo impulso a desarrollar mediciones adecuadas y a estimar la patogenicidad de prácticas sociales tan extendidas, como el uso de plataformas digitales, el teletrabajo, la telemedicina, la automatización de los procesos económicos, el adoctrinamiento político y la influencia omnipresente de las persuasiones ocultas de la publicidad y la propaganda.

LA DIMENSIÓN MORAL Y SOCIAL DE LA PSIQUIATRÍA

KALLIVAYALIL, R.A., GOGINENI, R.R., AKHTAR, S. (editores)

The Glow of Synthesis. Twelve Beacons of Light in Social Psychiatry.

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Fernando Lolas Stepke¹

Este libro recoge ensayos sobre doce personas cuyas contribuciones se juzgan importante para relevar la dimensión social de la psiquiatría y la salud mental. Salvo Norman Sartorius, aún activo, los demás son figuras históricas: Karen Horney, Erich Fromm, Erik Erikson, Geza Roheim, Margaret Mead, Emile Durkheim, Theodor W. Adorno, Joshua Bierer, George Morrison Carstairs, Ravi L. Kapur, Julian Leff.

Junto a una breve biografía, los textos destacan sus contribuciones a la antropología, la sociología, la crítica cultural, la psicología y la psiquiatría. Sin dudar de lo acertado de la elección de estos nombres, obviamente habría otros que podría haberse incluido.

El volumen se completa con un apéndice que resume vida y obra de otros pioneros, entre los cuales cabe mencionar a Juan Marconi, de Chile, Javier Mariátegui, de Perú, Julio Arboleda-Florez, de Colombia, por nombrar algunos latinoamericanos, además de figuras relevantes de Grecia, Reino Unido, India, Bulgaria, Australia, Japón y Alemania.

La primera conclusión que se impone tras la lectura de este volumen es que todos los biografiados fueron, de una forma u otra, moralistas. Esta vieja palabra resume la preocupación por las complejidades e incertidumbres de la vida humana en sociedad. También es destacable que en todos ellos la preocupación por la cultura como expresión de lo social fue determinante para destacar su influencia en las ciencias de la salud, el bienestar y la calidad de la vida. Cómo han sido recibidos y valorados sus aportes es tema de controversia. En la sección dedicada a “Psicoanalistas culturalmente inclinados” sorprende que los tres biografiados, Horney, Fromm y Erikson, de alguna manera se opusieron a las opiniones de Sigmund Freud, el “biólogo de la mente”, cuyas reflexiones culturales y antropológicas fueron producto de opiniones personales o evidencias incompletas. Sorprende también la azarosa vida de esas personas, incluyendo la notable biografía de Erikson, quien nunca conoció a su padre, o las resistencias que encontró Fromm para divulgar sus ideas a pesar de ser un polígrafo popular.

Las contribuciones de sociólogos y antropólogos (Roheim, Mead, Durkheim, Adorno) ilustran la fertilidad de disciplinas no médicas para la fundación de una “psiquiatría social”. Sorprende saber que la clásica obra de Durkheim sobre el suicidio no concitó mayor interés cuando fue publicada y que las aportaciones sobre estudios culturales de Roheim y Mead han sido parcialmente aceptadas por la comunidad psiquiátrica, probablemente por las barreras que imponen los lenguajes exclusivos y excluyentes de la especialización disciplinaria.

Ya en la sección sobre psiquiatras que hicieron de la dimensión social el eje central de sus preocupaciones se llega a observaciones de valor práctico. Joshua Bierer, fundador de la World Federation for Mental Health, tiene hoy valor institucional y conceptual. Castairs, Kapur, Leff y Sartorius han abogado, con mayor o menor fortuna, por ampliar horizontes en la práctica de la psiquiatría y en sus dimensiones epidemiológicas. Tal vez recordar la obra de Franco Basaglia no hubiera estado demás,

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como asimismo dedicar un estudio a otras personas que hicieron contribuciones a la labor comunitaria, la desinstitucionalización y la lucha contra el estigma asociado al trastorno mental, pero ello se repara en parte con las breves biografías incluidas en el Apéndice.

Es un volumen de gran valor porque toda consideración social es al mismo tiempo una reflexión moral y el trabajo de quienes están representados en este volumen puede considerarse desde varias perspectivas. Todas ellas complementarias del paradigma dominante de la psiquiatría médica tradicional, con su énfasis en los sustratos neurofisiológicos y bioquímicos del psiquismo, que recuerdan disputas ya superadas en la psiquiatría contemporánea.

MARTÍNEZ GÓMEZ, JESÚS ARMANDO y CABRERA-CABRERA, ANTONIO MARÍA (Coordinadores)

Bioética global y su impacto en el siglo XXI.

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Alberto García Gómez¹

En el contexto actual de crisis ecológica, desigualdad social y transformaciones tecnocientíficas aceleradas, el libro *Bioética global y su impacto en el siglo XXI* constituye una aportación coral y plural al pensamiento bioético contemporáneo. Coordinada por Jesús Armando Martínez Gómez y Antonio María Cabrera-Cabrera, esta obra colectiva reúne a más de veinte autores iberoamericanos que reflexionan sobre los fundamentos, desafíos y aplicaciones de la bioética global, desde perspectivas filosóficas, teológicas, jurídicas, sociales y científicas.

El volumen se organiza en cuatro partes que articulan un recorrido desde los fundamentos teóricos de la bioética hasta su aplicación práctica en contextos globales y tecnológicos.

La primera parte, “Introducción a la bioética global y sus fundamentos”, expone los marcos conceptuales y metodológicos que permiten comprender la transición de la bioética clínica a una bioética global. En el capítulo inaugural, Martínez Gómez y Gemma Fernández Pichardo reconstruyen la evolución de los principios de autonomía y responsabilidad, mostrando cómo la ética del respeto a la persona se amplía hacia la responsabilidad solidaria con toda forma de vida. Roberto Yenny García aborda el diálogo entre la bioética teológica y la bioética secular como condición para una ética global inclusiva, mientras Fernando Lolas Stepke examina el desarrollo de una “mentalidad bioética” en Iberoamérica. María Elizabeth de los Ríos Uriarte propone los principios de solidaridad, socialidad y subsidiariedad como claves para afrontar los desafíos del siglo XXI, y René Zamora Marín rescata el pensamiento ético cubano (Varela, Luz y Caballero, Martí) como expresión local de principios universales.

La segunda parte, “La bioética en el contexto contemporáneo”, integra contribuciones que examinan los aprendizajes éticos del COVID-19 (Miguel Kottow), la gestión global de recursos sanitarios (Patricia Mancilla Dávila), la bioética “en salida” hacia las periferias (Cabrera-Cabrera, Sánchez-Guerrero y Cerdio-Domínguez) y el pluralismo cultural (Eduardo Farías Trujillo). También destacan los análisis de Víctor M. Castaño sobre la dimensión institucional de la bioética y de Maldonado-Castellanos y Aguilar Navarrete sobre la “bioética ciudadana”, que amplía la deliberación ética a la participación social.

La tercera parte, “Ética aplicada a problemas globales”, desplaza el foco hacia los ámbitos socioambientales, comunitarios y biomédicos. Se abordan la relación entre pensamiento radical y diálogo bioético (Cerdio y Sánchez-Guerrero), la crítica a los imaginarios de la sostenibilidad neoliberal (Luna Nemeio), las terapias acuáticas y el derecho a la salud (Marccone Dapelo), la educación en derechos humanos en carreras de salud (Porras Araneda), los trasplantes faciales (Palomares Cantero) y la ética del cuidado en personas mayores (Mariscal Ureta, Pérez González y Keferstein).

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Finalmente, la cuarta parte, “Reflexión ética frente al desarrollo tecnológico”, plantea los retos que imponen la ciencia y la técnica contemporáneas. Ian Henríquez examina la relación entre *tékhnē, epistēmē* y regulación jurídica, y José Ramón Amor Pan cierra el volumen con una lúcida reflexión sobre “Verdad, belleza y bondad en la era de la inteligencia artificial”, donde propone una “bioética de la resistencia” frente a la fragmentación de la gobernanza tecnológica global.

La obra se distingue por su amplitud temática y pluralidad metodológica, conjugando enfoques filosóficos, teológicos, jurídicos y científicos. El hilo conductor es la noción de bioética global como horizonte integrador que supera los límites de la bioética clínica y busca responder a los desafíos planetarios de justicia, sostenibilidad y dignidad humana. Un aporte relevante es la relectura de los principios bioéticos —autonomía, beneficencia, no maleficencia y justicia— a la luz de categorías como responsabilidad, solidaridad y subsidiariedad, en continuidad con la Declaración Universal sobre Bioética y Derechos Humanos de la UNESCO (2005). Esta ampliación conceptual abre el camino hacia una ética pública global, en la que la responsabilidad individual se articula con la corresponsabilidad institucional y social.

También resulta significativa la integración de perspectivas latinoamericanas, tanto en la recuperación de tradiciones éticas locales (el pensamiento de Varela y Martí, por ejemplo) como en la atención a las desigualdades estructurales, la exclusión sanitaria y la pobreza ambiental. De este modo, el libro evita la homogeneización del discurso bioético y promueve un diálogo intercultural fecundo.

El volumen, por su extensión y diversidad, ofrece un panorama completo del estado actual de la bioética global, aunque su carácter misceláneo puede dificultar una lectura sistemática. Algunos capítulos se orientan más a la exposición histórico-conceptual, mientras otros desarrollan análisis aplicados con distinto nivel de profundidad. No obstante, la coherencia temática se mantiene gracias al propósito común de situar la bioética como “puente hacia el futuro” —en la expresión de Potter—, entre ciencia, ética y humanidad.

Destaca especialmente el equilibrio entre rigor académico y compromiso social, rasgo que otorga al libro una relevancia especial en el debate iberoamericano. Frente a la tecnocratización de la ética o la abstracción filosófica, los autores insisten en una bioética encarnada en la vida concreta de los pueblos y en los desafíos ecológicos y tecnológicos del siglo XXI.

Bioética global y su impacto en el siglo XXI es una obra de referencia para investigadores, docentes y profesionales interesados en los vínculos entre ética, ciencia, salud, medio ambiente y justicia global. Su enfoque interdisciplinario y su vocación de diálogo hacen de ella una contribución significativa a la consolidación de una bioética iberoamericana con proyección mundial, fiel a los principios de responsabilidad, solidaridad y respeto por la vida en todas sus formas.

Constituye, en suma, un esfuerzo colectivo por pensar la bioética desde el sur global, con mirada crítica, compromiso social y apertura intercultural. Por ello, su publicación por Tirant Humanidades representa un paso importante en la maduración académica del pensamiento bioético en lengua española y una invitación a seguir construyendo una bioética verdaderamente global, dialogante y humanizadora.

DECÁLOGO ÉTICO PARA LAS TECNOLOGÍAS EN SALUD

MARTÍN URRIALDE, J.A. (Coordinador)

Decálogo ético para la humanización y el uso de tecnologías en salud.

CEU Ediciones, Madrid (España), 2025. (ISBN: 979-13-87860-04-02), 112 págs.

Jesús Armando Martínez Gómez¹

La irrupción de las tecnologías digitales en la medicina y la atención de salud ofrece enormes posibilidades para mejorar el acceso a los servicios sanitarios y elevar la calidad y corrección del diagnóstico, los procesos terapéuticos, la prevención y la rehabilitación de enfermedades, pero también genera incertidumbres y riesgos que hoy son objeto de análisis en numerosas publicaciones que persiguen delinear los elementos esenciales de un marco ético y jurídico apropiado para su regulación. La obra *Decálogo ético para la humanización y el uso de tecnologías en salud*, coordinada por el Dr. José Antonio Martín Urrialde, es el resultado de una reflexión profunda que busca equilibrar las posibilidades inquestionables que brinda la aplicación de las tecnologías digitales en el sector salud con el imperativo de preservar los valores humanos que son intrínsecos a la práctica médica.

Con prólogos de Emiliano Blasco Doñamayor y Julio Zarco Rodríguez, cada uno de los diez capítulos de esta obra colectiva constituye un tópico imprescindible para el análisis en profundidad de la problemática que aborda: 1. “Bienestar integral y salud digital” (Antonio Piñas Mesa), 2. “La educación de la ciudadanía y de los profesionales” (José Luis Bimbela Pedrola), 3. “Los peligros de la tecnología sanitaria ante la pérdida de los valores humanísticos” (José Antonio Martín Urrialde), 4. “Inclusión y no discriminación” (Benjamín Herreros), 5. “Telemedicina para accesibilidad: un pilar en la humanización de las tecnologías sanitarias” (Carlos Royo Sánchez), 6. “Tecnologías y medicina centrada en la persona” (Fernando Lolas Stepke), 7. “Seguridad y confidencialidad de los datos en tecnologías sanitarias: un pilar clave en la humanización” (Carlos Royo Sánchez), 8. “Interoperabilidad y eficiencia” (Carlos Gallego Pérez), 9. “Formación integral de profesionales” (Tomás Chivato Pérez), 10. “Mecanismos de evaluación para medir el impacto de las tecnologías en la humanización de la atención sociosanitaria” (José Antonio Martín Urrialde).

Fiel a su estructura y lógica, el texto comienza analizando la estrategia mundial de la OMS para el fortalecimiento de los sistemas de salud mediante la aplicación de tecnologías de salud digital como medio para hacer realidad la aspiración de salud para todos, alertando sobre los peligros de la medicina de perfección. A continuación se adentra en las dimensiones del concepto de salud desde una perspectiva integradora, que incluye cinco dimensiones esenciales (ética, física, emocional, social y espiritual), las cuales deberán ser atendidas para lograr preservar el carácter humanista de la praxis médica en la era tecnológica actual, que demanda un modelo médico centrado en la persona, en la integración de la IA con la supervisión humana y criterios de justicia que permitan una mayor inclusión y equidad en la distribución de los recursos de salud y las prestaciones médicas, que se podrían ver favorecidas por el uso adecuado de la telemedicina.

Desde la concepción de la medicina como saber orientado a la praxis (praxis tecnológica), que se encuentra en la interfaz entre ética, política y tecnología, se hace un llamado a centrar la atención médica en la persona —verdadero fin y no medio del desarrollo tecnológico—, para ayudarla a promover su

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bienestar, sanación y curación, previniendo para que este fin no se vea obstaculizado por la medicina del deseo. Se alerta sobre la necesidad de fortalecer la seguridad informática como vía para la protección de los datos, la privacidad y la información relativa al estado de salud y enfermedad de los usuarios de los servicios de salud, y se proponen directrices éticas para el logro de una interoperabilidad que propicie el mejor uso y eficacia de la información disponible. En sus capítulos finales, los autores se detienen en el análisis de la educación médica y en la necesidad de preservar su sentido humanista a través de un modelo formativo centrado en la persona y su dignidad, en la integración de las competencias clínicas con la formación en valores para el desarrollo de actitudes humanitarias en los profesionales de la salud, así como en la implementación de técnicas que permitan la evaluación cuantitativa y cualitativa del impacto de la tecnología digital en la humanización de la atención médica.

Aunque los temas son tratados con profundidad y gran rigor científico, la obra no se dirige sólo al público especializado. Sus autores apuestan por un humanismo digital participativo como sustento del desarrollo tecnológico de la medicina, “donde máquina y humano, tecnología y humanismo se den la mano de una manera armónica, integral e interdisciplinar”.

No cabe duda de que se trata de un manual de referencia que ofrece una guía ética de gran valor para orientar la labor de investigadores, médicos, profesores, responsables de políticas públicas y legisladores, a partir de sólidos referentes morales. Constituye, además, un texto de obligada consulta para quienes aspiran a seguir construyendo una medicina centrada en el ser humano y su dignidad, en el marco del dinámico y complejo contexto tecnológico en el que se desarrolla la práctica médica del siglo XXI.

MARTÍNEZ GÓMEZ, JESÚS ARMANDO y PÉREZ GONZÁLEZ, EDGAR (Coordinadores)

Neurociencias, Inteligencia Artificial, Ética y Derecho

Editorial Tirant humanidades, 2025

Antonio Muñoz Torres¹

El libro reúne una serie de aportes interdisciplinarios que combinan temas como tecnologías emergentes, inteligencia artificial, neurociencias, ética, bioética, filosofía del Derecho y Derecho, con la intención de analizar críticamente cómo los avances tecnológicos y científicos están transformando nuestra percepción y concepción de la persona, la libertad, la responsabilidad, la democracia, los derechos humanos y la vida social.

Se plantea una reflexión principal: no estamos ante una mera “tecnología adicional”, sino ante transformaciones que alcanzan cimientos de nuestra vida individual y colectiva, por ejemplo, el concepto de “persona”, la percepción de la realidad, la valoración moral, la cognición, las nuevas formas de interacción, la salud mental, la justicia, etc.

El libro se compone de diez secciones con los siguientes ejes temáticos:

- Fundamentos de la Inteligencia Artificial IA
- Incidencia de las neurociencias, neurotecnologías e inteligencia artificial en la ética y la bioética.
- La interpretación de la libertad humana y de la inteligencia humana, especialmente frente a instrumentos tecnológicos que modifican o amplían nuestras capacidades.
- La mejora humana, el transhumanismo o las implicaciones de “mejora” (mejora cognitiva, física, neurológica) como desafío ético-jurídico.
- El funcionamiento de la democracia, la veracidad de la información, la participación política, en un contexto tecnológico donde la IA y las neurotecnologías interaccionan.
- Salud mental, prevención del suicidio, vulnerabilidad de ciertos sectores poblacionales, neurodiversidad.
- Justicia penal, seguridad ciudadana, ámbito fiscal: la penetración de tecnologías en estos campos y sus implicaciones normativas.
- Investigación científica, protección y redefinición del contenido de los derechos humanos, es decir, ¿cómo los derechos humanos se transforman o deben transformarse frente a estas nuevas tecnologías?
- Educación en el siglo XXI: cómo la neurociencia, la IA y las tecnologías emergentes afectan los procesos educativos, aprendizaje, docencia y quizá la construcción del conocimiento (mencionado en la sinopsis).

Las aportaciones clave de esta obra son, por una parte, la interdisciplinariedad, que destaca por cruzar las barreras entre Derecho, ética, filosofía, ciencias cognitivas y tecnología, enfoque necesario pues

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estas cuestiones requieren ser abordadas desde la óptica de más de una disciplina. Por otra parte, la perspectiva humana-centrada en la persona. Aunque la tecnología emergente es el motor del análisis, el libro hace un llamado a colocar «la persona», «la dignidad humana» y «el bien común» como ejes normativos.

Otro aporte importante es el relacionado con el marco normativo y ético revisitado: No basta con aplicar marcos jurídicos existentes (la obra sugiere que debemos repensar, renovar marcos éticos y jurídicos para afrontar los retos de tecnologías disruptivas, neurotecnologías, IA, etc. En el campo de los derechos humanos, se hace un llamado al reconocimiento de vulnerabilidades y de la transformación social: el libro no solo se queda en lo tecnológico o lo jurídico abstracto, también aborda ámbitos concretos, como salud mental, neurodiversidad, vulnerabilidad de ciertos sectores, lo que aporta un matiz más social y humano. Finalmente, pero no menos importante, se percibe que los autores consideran que estos cambios no están “en un futuro lejano” sino que ya están afectando nuestra vida social, jurídica, personal, y requieren respuestas ya (consciencia de la urgencia).

Neurociencias, Inteligencia Artificial, Ética y Derecho hace un llamado al estudio de realidades novedosas y complejas, como los campos de neurociencias y neurotecnología, junto con IA, que evolucionan vertiginosamente. Una obra como esta se enfrenta al reto de mantenerse actual y vigente frente a tecnologías que cambian aceleradamente y suscitan nuevas preguntas en diferentes áreas de la sociedad y el saber humanos. Por otra parte, al juntar muchas disciplinas (pluralidad de voces), pueden surgir tensiones metodológicas (por ejemplo, entre filosofía y Derecho, o entre ciencia y ética). Eso es un riesgo pero también una fortaleza: los problemas complejos requieren de una comprensión profunda. Asimismo, se pretende dar un paso hacia la aplicabilidad práctica, donde las reflexiones éticas y teóricas son adecuadas, pero el salto hacia políticas públicas, regulaciones o implementaciones concretas es siempre complejo. La obra invita a ese salto, pero dicho salto es un desafío. Finalmente, al tratar muchos temas, existe el riesgo de que cada tema se trate de manera más superficial que si se hubiera hecho una obra monográfica. Pero ello también convierte al libro en una panorámica valiosa.

El libro va dirigido a un público diverso, investigadores y académicos en Derecho, ética, filosofía del Derecho, ciencias cognitivas, neurociencias, tecnologías disruptivas, política, así como a profesionales de la justicia, reguladores, responsables de políticas públicas que se ocupan de tecnología, salud, educación, derechos humanos y también estudiantes avanzados que buscan comprender la intersección entre tecnología emergente (IA), ética, Derecho y neurociencias. Finalmente a interesados en la reflexión sobre cómo la IA y las neurotecnologías cambian la sociedad, los derechos humanos y la persona.

Dado que vivimos ya en plena era de la IA, donde la neurotecnología empieza a introducir nuevos modos de influencia sobre el pensamiento, la percepción y la conducta, este libro aparece en un momento oportuno. Plantea preguntas fundamentales: ¿qué significa ser libre en un mundo de algoritmos y neurotecnología? ¿Qué ocurre con la responsabilidad cuando las decisiones —o al menos los apoyos a las decisiones— pasan por sistemas cognitivos ampliados o híbridos? ¿Cómo proteger la dignidad humana cuando la tecnología puede intervenir directamente en los procesos neurocognitivos?

En resumen, *Neurociencias, Inteligencia Artificial, Ética y Derecho* es una obra que se atreve a mirar los cruces más inquietantes entre la tecnología avanzada y la vida humana desde un enfoque riguroso e interdisciplinario. No es únicamente un análisis técnico ni jurídico: es una invitación a la reflexión sobre qué tipo de futuro queremos, cómo las estructuras jurídicas y éticas deben adaptarse y cómo se debe proteger lo que nos hace humanos frente al avance tecnológico.

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