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SOBRE JUSTIFICACIONES MORALES. LA CONVENIENCIA DE UN "*AXIOGRAMA*" EN LAS DELIBERACIONES BIOÉTICAS.

Fernando Lolas Stepke[1]

La ética es un "juego de lenguaje" que justifica (no solo fundamenta) usos, costumbres y tradiciones estimadas correctas o buenas. La idea de una "moral común" universal supone normas de conducta compartidas por todas las personas, como dicen Beauchamp y Childress, "comprometidas con la moral".

La justificación de las afirmaciones sobre moral común puede ser empírica, teórico-normativa y conceptual. En cada una de estas formas de justificación el análisis debe contemplar cómo se especifican y ponderan los principios (explícitos o implícitos) usados para formular directrices; se supone que la racionalidad puede sustentar afirmaciones de naturaleza moral y las condiciones bajo las cuales serán relevantes. Muchas investigaciones en bioética son estudios de psicología social, examen histórico de prácticas o examen de la relevancia de algunas generalizaciones en condiciones específicas. Las personas suelen operar en la vida diaria empleando argumentos deontológicos (deberes) o teleológicos (consecuencias); a veces se ignora el basamento caracterológico de las virtudes. Éstas, como "excelencias" de la vida práctica, dependen del carácter y éste a su vez de los hábitos. Hábitos virtuosos engendran caracteres virtuosos. Tal es el sentido de las palabras griegas que aluden a lo ético: hábito, costumbre, carácter.

Personas consideradas virtuosas o excelentes, según las circunstancias, pueden cometer actos impropios, punibles o condenables. A la inversa, personas comunes y corrientes pueden realizar acciones elogiables o meritorias. La casuística, aquella que Blaise Pascal criticaba en los jesuitas de su época, toma en cuenta la circunstancia (*circum-stare*, lo que rodea a una cosa) y es sabido que la consideración de la circunstancia puede modificar el juicio moral sobre las acciones y que el discernimiento moral no consiste solo en aplicar, especificar y ponderar principios sino también en considerar qué personas realizan los actos, sus finalidades y qué medios se emplean. Buenos medios y buenos fines son materia de discrepancias entre personas. Cuando Kant afirma que lo admira el cielo estrellado sobre su cabeza y la ley moral dentro de ella apela a una experiencia cotidiana. La conciencia moral es preconceptual y casi no precisa discernimiento. Pero la tarea del evaluador es discernir y en este discernir se da siempre alguna forma de valoración. Una disciplina evaluativa es inseparable de un complejo sustrato de emoción y juicio, del que no está ausente la dimensión estética. Aunque no todo lo bello es bueno y lo bueno a veces no satisface ni las preferencias personales ni los sentidos, es imposible negar que la mayoría de los enjuiciamientos morales y la deliberación ética comparten un sustrato emotivo que compromete y obliga. Como afirmaba Klages, el "alma" no es lo mismo que el "espíritu".

En los usos más habituales del discurso bioético se trata de "aplicar" (especificar y ponderar) normas que se considera vinculantes para personas que comparten un universo valórico. Muchos trabajos sobre ética biomédica consideran aplicaciones a quienes están en el papel social de "pacientes", "enfermos" o "participantes en una investigación". Incluso las refinadas reflexiones de la medicina antropológica de Heidelberg no siempre contemplaron el carácter diádico o "multiádico" de la relación terapeuta-enfermo o investigador-partícipe, algo que Fritz Hartmann complementaba con una "antropología del cuidado médico" (ärztliche *Anthropologie*). Y es que pareciera ser que el "mantra de Georgetown" (autonomía-beneficencia-no maleficencia y justicia) no se aplica igual a todos los miembros de la relación interpersonal y plantea conflictos en algunos entornos institucionales.

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El número de principios relevantes para evaluar comportamientos y prácticas, anclados en valores instrumentales o esenciales, puede ampliarse a otros como reciprocidad, vulnerabilidad o solidaridad: Su uso está tan extendido que el proceder bioético se ha “tecnificado” al punto de que se considera apropiado evaluando cumplimiento o transgresión y la solución de conflictos entre principios. Aun suponiendo que la moral común y los derechos humanos fueran universales y respetados siempre (lo cual haría paradójico tener que escribirlos y recordarlos) su “internalización” personal puede variar. Para algunas personas y culturas, la relevancia de cada principio puede diferir de otras. Respetar la autonomía, por ejemplo, no significa que se la valore igual por quienes participan en la deliberación y en toda circunstancia.

La configuración individual de la internalización (o apropiación efectiva) de los principios puede diferir entre quienes participan de encuentros interpersonales. Aunque haya acuerdo en los actos correctos, los motivos por los cuales éstos con correctos o permisibles puede variar.

Sería un buen programa de investigación en axiografía empírica reflejar estas diferencias en una forma que permitiera rápida comparación entre individuos y culturas. La idea de un “axiograma” que algunas veces discutimos con Hans-Martin Sass sigue siendo atractiva. Tener una *representación gráfica* del universo valórico (en términos de relevancia de principios) de médicos y enfermos podría agregarse a la historia clínica, junto al ecocardiograma, el electroencefalograma o el hemograma. Quizá contribuyera a perfeccionar la conformación de díadas terapéuticas eficaces o evitar malentendidos que, basándose en palabras semejantes, no reflejaran horizontes de expectativas compartidas.

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REFLECTING ON NARRATIVES VIA NARRATIVE MEDICINE: EMOTION THEMES DERIVED FROM NARRATIVES OF WOMEN WITH CANCER

Merih Anar Öztoprak[1]

Abstract: *Narrative medicine* provokes physicians' deeper understanding and empathy for both patients and other healthcare providers. Materials that are used to provoke emotions and improve empathy. The aim of this textual close reading and literary analysis work is to discuss examples of life-writings and experiences of cancer patients from the perspective of emotional awareness and their presence during patient-health care professional relationship.

To achieve an understanding of the texts and emphasize difficult emotional themes, text analyses are grouped in a thematically manner.

The results of the narrative document analysis are categorized and interpreted as difficult emotional themes. Sub-themes are created as psychic pain, fear, shame, and anger. These emotional themes are discussed in terms of patient-physician relationship, empathy and the methods of Narrative Medicine.

We may create new alternative roads that can alter and transform patient-physician relations to a more humanistic structure, by close reading and reflective writing. Literary and textual exercises are need to be done regularly to gain narrative competence. Qualitative studies are needed to be done about the reflections of students, health care providers, and patients.

Keywords: narrative medicine, emotional awareness, life writing, illness narrative

Reflexiones sobre relatos desde la Medicina Narrativa: Temas emocionales derivados de las narrativas de mujeres con cáncer

Resumen: La medicina narrativa promueve en los profesionales de la salud una mayor comprensión y empatía, tanto hacia los pacientes como hacia sus colegas. Se utilizan materiales para generar emociones y mejorar la empatía. Este artículo, de análisis literario y lectura reflexive, tiene como propósito analizar ejemplos de relatos de vida y experiencias de pacientes con cáncer desde la perspectiva de la conciencia emocional y su presencia en la relación paciente y profesional de la salud.

Para comprender los textos y enfatizar los temas emocionales complejos, los análisis se agrupan temáticamente.

Los resultados obtenidos del análisis de documentos narrativos son categorizados e interpretados como categorías emocionales complejas, que incluyen subtemas como el dolor psíquico, el miedo, la vergüenza y la ira. Estos aspectos emocionales se discuten en términos de la relación médico-paciente, la empatía y los métodos de la medicina narrativa.

A través de la lectura atenta y la escritura reflexiva surge la posibilidad de crear nuevas vías alternativas que puedan reconfigurar y transformar la relación médico-paciente hacia un modelo más humanista. Es necesario realizar ejercicios literarios y textuales con regularidad para desarrollar la competencia narrativa. Por último, resulta necesario realizar estudios cualitativos que recaben reflexiones tanto de estudiantes, profesionales de la salud y pacientes.

Palabras clave: medicina narrativa, conciencia emocional, escritura de vida, narrativa de la enfermedad

Refletindo sobre narrativas via Medicina Narrativa: Temas de emoção derivados de narrativas de mulheres com câncer

Resumo: *Medicina narrativa* provoca compreensão aprofundada e empatia dos médicos por pacientes e outros prestadores de cuidados à saúde. Materiais que são usados para provocar emoções e melhorar empatia. O objetivo deste trabalho de leitura textual atenta e análise literária é discutir exemplos de escritos de vida e experiências de pacientes com câncer de uma perspectiva de consciência emocional e sua presença durante uma relação paciente-profissional de cuidados à saúde.

Para alcançar uma compreensão dos textos e enfatizar temas emocionais difíceis, análises de texto são agrupadas de maneira temática.

Os resultados da análise documental narrativa são categorizados e interpretados como temas emocionais difíceis. Sub-temas são criados como dor psíquica, medo, vergonha e raiva. Esses temas emocionais são discutidos em temos da relação médico-paciente, empatia e os métodos da Medicina Narrativa.

Nós podemos criar novos caminhos alternativos que podem alterara e transformar relações médico-pacientes para uma estrutura mais humanística, por meio de leitura atenta e escrita reflexiva. Exercícios literários e textuais precisam ser feitos regularmente para ganhar competência narrativa. Estudos qualitativos precisam ser feitos sobre as reflexões de estudantes, prestadores de cuidados à saúde e pacientes.

Palavras-chave: medicina narrativa, consciência emocional, escritos de vida, narrativa de doença

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Introduction

Narrative medicine is defined as 'medicine practiced with the narrative competence to recognize, interpret, and be moved to action by the predicaments of others*(1)*.' It provokes physicians' deeper understanding and empathy to both patients and other health care providers, and evolves their medical practice through the aspect, which does not limit a patient's illness story merely as medical history. Gaining this narrative competence requires humane and holistic approach to patient stories, effective listening skills, close reading and critical analysis of texts, and reflection on one's own practices. Founder of the method, Rita Charon, resonates the need for narrative competence as; 'Despite such impressive technical progress, doctors often lack the human capacities to recognize the plights of their patients, to extend empathy towards those who suffer, and to join honestly and courageously with patients in their struggles toward recovery, with chronic illness, or in facing death'*(2)*.

Mita Banerjee points out some features of life writing, which are agency and authenticity, by paraphrasing Joanna Shapiro's interpretative approach to illness narratives, such as readers' perspective and subjectivity, and the problem of telling a 'true' story from the accounts of the author/narrator, she also states her own interpretation about how reading first person autobiographical texts, and fictional writings differ in the essence: 'There's, of course, a subjective dimension to this experience as "objective truth" a dimension which exposes objectivity as a myth in the first place. Yet, I believe that there is a sense in which life writing accounts differ from fiction in the urgency they convey…'*(3)*. In order to understand the creation of an illness narrative, we need to interrogate, "how people, in the act of their lives, might change the stories they tell, might gain access to other cultural scripts, might come to understand themselves differently"*(4)*, but we, as the addressee, also need to ask how we're being aimed to attach to a person's illness narrative.

Autobiographies and patient illness narratives can enable us to witness one's experiences, in the way that the narrator lets us witness. We can interact with people's reflective emotions and thoughts about their situation. We can analyze different perspectives of her narration and critically think about 'how' these perspectives function for 'us' both as readers and health care providers. Charon emphasizes the importance of illness naratives or pathographies as a space for patients to tell their pain experience, to make their voice heard and to escape the dominance of disease on them*(2)*. Literary works and academic papers about pathographies are becoming a field of analysis about patient experiences and reconstructions of these experiences. Conveying an experience is a unique and self-reflective process, which is also highly subjective, and personal. That's why it's fundamental to avoid interpreting illness narratives only as a material, which conveys a 'meaning' via a constructed text. Additionally, we (as clinician and as readers) need to see these narratives as a journey that we witness and accompany and an experience of emotions that we convey through our own reflective texts. "We are all poets, narrators who symbolically give meaningful form to experiences, and in so doing craft and perform our sense of self and our worlds"*(5)*.

Healthcare providers who are emotionally aware and resilient are less affected by the negative outcomes of these factors. Medical education in all stages should contribute to emotional self-awareness skills. Joanna Shapiro defines emotional self-awareness as 'emotional honesty', and claims that 'little effort is exerted to develop emotional honesty in medical students or residents'*(6)*. To develop emotional honesty, first, we should understand what emotion is and how it evokes. Lynn Worsham offers a definition for emotion, which includes a social and historical judgment and a strong bodily experience. Our embodied responses like emotions, are our connections to 'social order and its structure of meaning'. So, healthcare providers should first analyze themselves and their relationality in society by means of their identity and its reflection on these bodily experiences. With the help of reflective thinking, textual analysis and writing health care providers can reach the source of their own emotional experiences. Illness narratives, wich are a genre of reflective personal expression, sketch new roads for healthcare providers to improve their empathic reflective skills.

Aim and Method

This narrative study aims to provide a comprehensive example of interpreting and reflecting on the life writings of women with cancer using emotional expressions. It is considered as the introductory study of first author's medical education PhD dissertation on Narrative Medicine and empathy education.

This study is designed as a narrative research. Data has been collected from published literary and reflective texts. To achieve a meaningful discussion from the texts and emphasize emotional themes, texts have been iteratively read and relevant topics groupe thematically.

Scientific, ethical and citation rules were followed in the writing process of this study; No falsification was made on the collected data and this study was not sent to any other academic publication medium for evaluation. Ethics committee approval was not obtained in the study, since data was not collected in a way that required ethics committee approval.

Emotion Themes

Psychic Pain

Every disease brings psychic pain of different levels not only to the patient but also to the people who care for that patient. These people are mostly physicians, nurses, caregivers, and at most the patient's family members. One of the most difficult and painful diseases that we encounter is cancer. Cancer is the insidious enemy of our age. Scientific journals are full of statistics about treatment of the disease and survival chances of patients. Numbers, which actually represent people, whose lives had entirely changed, mostly mean an everyday routine in a clinic, an academic advancement for a title, or a professional development for most of the clinicians. However, the emotions of clinicians are invisible or buried deep down. A person fighting cancer, especially during the active state of disease, is the person who experiences one of the most vulnerable and defenseless periods of life. Considering this life-changing 'chronic' experience is eternal for the survivor, one must develop new, regulatory, imaginative, and creative approaches to the new 'self', like establishing new maps with new roads to reach into the depths of mind and soul. These new ways of perception and thought can change a person's relationship entirely both within and out. Also, it's relevant to the survival mechanisms that a person usually uses before to cancer diagnosis. That's why for a clinician, it's firstly important to understand a person's history and character which are in use to deal with major physical and emotional trauma. Mainly this awareness leads to an ethical, respectful, and informative relationship between patient and clinician, in favor of the patient's autonomy and beneficence.

Here I'll discuss Audre Lorde's painful and traumatic cancer experience both as a self-healing process, and a social responsibility towards other women who share the same traumatic illness experience. Lorde was one of the most influential black, women, lesbian, and feminist, poets of the 20th century. In her bio mythography of how she became a poet, "Zami: A New Spelling of my Name", which she wrote long before her illness, she conveys her self, her otherness, and the different and intersecting components of her identity, within the time and space she's been living by these sentences: "Being women together was not enough. We were different. Being gay-girls together was not enough. We were different. Being Black together was not enough. We were different. Being Black women together was not enough. We were different. Being Black dykes together was not enough. We were different"*(7)*. The very first sentence of her 'The Cancer Journals' reflects the same approach to self-representation, from a different perspective. "Each woman responds to the crisis that breast cancer brings to her life out of a whole pattern, which is the design of who she is and how her life has been lived"*(8)*. She's also expressing her purpose of writing her cancer experience as a voice to be recognised, and respected. Her voice reflects the warrior within that she has been carrying through her lifetime. In addition, Lorde expressed an influential autobiographical agency, with an informative, insubordinate and transformative style of writing, to uncover the inequalities within the healthcare system by telling her experiences out loud. Her ideologic 'I's in her text reflects the clues of her attitudes towards the issues of gender, race, social discrimination, class and policies about community health:

"I do not wish my anger and pain and fear about cancer to fossilize into yet another silence, nor to rob me of whatever strength can lie at the core of this experience, openly acknowledged and examined. For other women of all ages, colors, and sexual identities who recognize that imposed silence about any area of our lives is a tool for separation and powerlessness, and for myself, I have tried to voice some of my feelings and thoughts about the travesty of prosthesis, the pain of amputation, the function of cancer in a profit economy, my confrontation with mortality, the strength of women loving, and the power and rewards of self-conscious living."

In addition, we can see how Lorde chooses to transform her emotions related to cancer, to create and address a community of shared experience. Her healing through writing is extending to a community of suffering women. She is aware of her detachment from her 'familiar identities' that she had known before cancer. She chooses this community that resolves the deep and estranged isolation. By giving voice to this community, she becomes familiar to her new 'self'.

Via her journal, Lorde is speaking in a rebellious voice, against discrimination that she has been subjected to. *"It hurts when even my sisters look at me in the street with cold and silent eyes. I am defined as other in every group I'm a part of. The outsider, both strength and weakness."* Being an outsider enables her to connect with her body from a reasonable distance. However, this causes alienation and consolidates her feeling of otherness. Lorde manages to disentangle the intense and complex feelings by writing and then reflecting on her texts. This awareness of the pain of otherness is the first step of communicating with the women who are also 'other'; sharing her pain and recovery, realize her changing priorities, and finding her stability again:

"Is this pain and despair that surrounds me a result of cancer, or has it just been released by cancer? I feel so unequal to what I always handled before, the abominations outside that echo the pain within…. I must let this pain flow through me and pass on….I need to remind myself of the joy, the lightness, the laughter so vital to my living and my health. Otherwise, the other will always be waiting to eat me up into despair again. And that means destruction."

Prosthesis is mostly offered to remove the visional inequalities. "…pain and all, expresses itself in the highly sexualized hegemony of denial and silence, signified by prosthetics." Lorde refuses to stay silent, and gives voice to her pain, fear and anger. She confronts the new state of her body and self, being aware of the value of staying still alive she manages to focus on and examine her 'real' body after mastectomy, by rejecting prosthesis. What traumatizes her again while she's in a progress of stabilization, is a nurse that she encounters during her first doctor visit after operation:

'When I walked into the doctor's office, I was really rather pleased with myself, all things considered, pleased with the way I felt, with my own flair, with my own style. The doctor's nurse, a charmingly bright and steady woman of about my own age who had always given me a feeling of quiet no-nonsense support on my other visits, called me into the examining room. On the way, she asked me how I was feeling.

"Pretty good," I said, half-expecting her to make some comment about how good I looked.

"You're not wearing a prosthesis," she said, a little anxiously, and not at all like a question.

"No," I said, thrown off my guard for a minute. "It really doesn't feel right," referring to the lambswool puff given to me by the Reach for Recovery volunteer in the hospital.

Usually supportive and understanding, the nurse now looked at me urgently and disapprovingly as she told me that even if it did not look exactly right, it was "better than nothing," and that as soon as my stitches were out I could be fitted for a "real form."

"You will feel so much better with it on," she said. "And besides, we really like you to wear something, at least when you come in. Otherwise it´s bad for the morale of the office."'

What we do, as health care 'professionals', is mostly coding some procedures that should be completed systematically. For this nurse, Lorde is still an 'incomplete job'; the mastectomy procedure has not been completed yet, because the patient is not wearing a prosthesis that will normalize her look. For us, after the procedure, the patient 'must' be very normalized to talk about the successful treatment. What we usually forget is what 'successful treatment' means, by ignoring the feelings and experiences of our patients. The more dramatic expression is that this nurse is aware of her feelings of discomfort, and she reflects them to Lorde via every way of communication; with her ignorant and disrespectful words, and with her disapproving mimics and gestures. Also, for Lorde, the nurse's words are the very symbol of an imposed figure of women in a society where the female body is objectified as a symbol of beauty. To Lorde, these are intensifying her feeling of otherness, her psychic pain. However, determined to stay as a 'survivor' and a 'warrior', Lorde refuses to connect new emotional roads that are established on the pain of otherness and incompleteness. She is familiar with rejecting the rules of patriarchy, and she claims whole control over her body, defending her autonomy:

'I refuse to have my scars hidden or trivialized behind lambswool or silicone gel. I refuse to be reduced in my own eyes or in the eyes of others from warrior to mere victim, simply because it might render me a fraction more acceptable or less dangerous to the still complacent, those who believe if you cover up a problem it ceases to exist. I refuse to hide my body simply because it might make a woman-phobic world more comfortable.'

Professional identity formation is an important topic that medical educators are researching effective methods to teach to health care professionals. In Lorde's experience, the nurse ignores her patient's feelings because she is trying to deal with her own emotions, as a woman at some time in her life, may need a mastectomy, as a woman who would have had a prosthesis if she needed the procedure. She may not even be aware of the source of her fears. She fails to react with her professional identity and respects the autonomy of her patient.

Fear

We should understand that starting from the moment of diagnosis; fear is going to be within for a cancer patient, even though she manages to survive. Death becomes more factual, priorities change, 'self' returns to another being, and another form of life. This alienation from the 'self' does not happen suddenly, and it depends on how a person relates to this new condition. Fear is constant and haunting. It may not disable the survivor, but paranoia and insecurity against the flow of life may traumatize repeatedly. One striking example is from Rita Charon, which she had experienced during her practice:

'I saw a patient in the office a few weeks ago. She had been diagnosed with breast cancer around twenty years ago, had a lumpectomy with five years of tamoxifen and was told she was cured. Recently, she developed a second cancer in the same breast. She treated this recurrence very matter-of-factly, submitting to a mastectomy, declining breast reconstruction, saying she was too old to need that. She recovered from the disfiguring surgery quickly, noncomplainingly.

Then she began to worry that the cancer would come back again. She felt new lumps in the mastectomy scar and growths in the soft tissue under her arm. She was terrified that it would come back. She visited either the breast surgeon or me every other week. We did ultrasounds and tested her blood for cancer markers. We both kept telling her she was fine, that after an operation tissues shift as they heal, that her cancer markers were stable. She could not feel reassured, and so she felt we were deceiving her'(9, 10).

Charon becomes aware of the patient's fear of death, and after explaining what death means to herself, she also offers the patient to stand up with her, to accompany her during the lonely journey that she has been going through. She adds while reading her visit records about this patient: "I described what the patient had been going through. I described my assessment of the meaning of her fear of a third cancer, explaining that our role as her doctors was to stand with her in her fear. What they experience is a shared network of strong emotion, and fear. Charon is sensitive to the needs of her patient because she can feel the same fear and decides to share it with her patient instead of burying it down into the depths of her mind. She realizes that she connects with the patient's feelings with the help of the text (the hospital record) that she created. After this experience, she feels a strong need to confirm the connection and calls her patient. Her patient's response of being 'healthier and less afraid' causes her to interrogate different ways of communication through a mystical approach:

"Perhaps by virtue of the narrative work we do, we clinicians can expose the cosmic connections between medicine and all the other human enterprises that give and receive accounts of self, that enter through story-telling into contact, into relation, into world-making."

Audre Lorde also mentions in 'The Cancer Journals' how she managed to live, create and produce with the presence of fear but without being disabled by it:

'…fear and anxiety are not the same at all. One is an appropriate response to a real situation which I can accept and learn to work through just as I work through semi-blindness. But the other, anxiety, is an immobilizing yield to things that go bump in the night, a surrender to namelessness, formlessness, voicelessness, and silence.'

Mostly the main problem is to continue living psychologically healthy after a period of trauma. Post-traumatic stress disorder (PTSD) is a disorder that develops in some people who have experienced a life-changing, dangerous event. In Lorde's situation, the most prominent source of stress and fear is facing death. It is natural to feel afraid during and after a traumatic situation. Fear triggers many split-second changes in the body to help defend against danger or to avoid it. This "fight-or-flight" response is a typical reaction meant to protect a person from harm. Nearly everyone experiences a range of reactions after trauma, yet most of them manage to recover and survive. However, those who continue to experience problems because of PTSD may feel stressed or frightened even when they are not in danger.

As far as we know, emotions are usually contagious via senses such as vision, touch or sound. However, the transmission may be so subtle that we may not be aware that we are infected unless we feel it. Anxiety is one of those emotions that contaminates us via trembling hands, purple halos under eyes, frequent breaths, trembling voices, sweating, flushing, crying or sometimes a frozen silence. It is sneaky and reminds to us, to both patients and clinicians, when we do not expect it to happen. Therefore, it disables us, and blocks our communication both with ourselves and with others we encounter. It deepens alienation and isolation. Lorde manages to deal with anxiety through techniques of mindfulness. She explores the symptoms of anxiety, and finds other feelings to replace them like relaxation. She constructs new emotional roads, which are connecting her traumatic experiences to her presence more healthily and calmly:

'The visualizations and deep relaxing techniques that I learned from it help make me a less anxious person, which seems strange, because in other ways, I live with the constant fear of recurrence of another cancer.'

Shame

Cancer patients encounter too many uncomfortable and intrusive procedures starting from the diagnosis to the follow-up. Becoming naked, someone touching your body, and asking intimate questions, are some invasive procedures. All of these can make a patient feel invaded by strangers. Even though these invaders can be from a patient's family or relatives, they are mostly doctors, nurses, and caregivers. Susan Gubar who is a literary scholar, and has been dealing with ovarian cancer since 2008, tells her story and so many inspirational stories on her web page column in the New York Times named 'Living With Cancer'. Gubar explains how uncomfortable she feels when someone touches her body, and how her doctors handle this sensitive choice of hers, neither leaving her examination incomplete nor damaging her possession over her own body:

'Throughout 10 years of cancer treatment, I have wondered how the considerate physicians, nurses and technicians I encounter manage not to violate my sense of myself, especially because I have always felt anxious about being touched by strangers — even in benign circumstances'(11).

Procedures are more complicated, mostly when they are also physically painful. Parts of bodies are sacred and exposing them to strangers for one's own sake is a kind of revelation. However, for patients, it is hard to perform these types of rituals as a routine, daily happening, especially when conditions are more difficult than we assume. For patients, especially with cancer, every follow-up visit, and every diagnostic or treatment procedure is some kind of exam or trial where doctors are examiners or judges. Their bodies will be assessed and evaluated for a decision to pass or fail, and what if they fail? This is the haunting question that determines how she'll be living the rest of her life.

'On numerous occasions, we have to be prodded and pierced. Our skin is shaved and painted, our bodies sliced open, various growths excised, sundry organs lopped off, and then we get stapled or stitched back together. At subsequent office visits, fingers press into our flesh, pushing into mouths, necks, armpits, breasts or bellies. Without any preparation, we must devise tactics for dealing with the physical intimacy of treatment'.

I guess that every woman remembers her first gynecologic examination. The invader transvaginal ultrasound device passes the barrier of perineal muscles and reaches the warm entrance of the cervix, conqueror! As Gubar emphasizes, during this kind of intimate relationship between a doctor and a patient, the patient's body becomes the agent of a way of communication. However, only the doctor would understand the monologue, even if sometimes it's an inner monologue. Gubar refuses the one-way feature of this interaction and changes it into a dialogue, a more proper and fair sharing. As an 'experienced' patient she finds ways to build bridges, to share the momentary microclimate, to create new roads of emotional maps. We as physicians, have a lot to learn from our patients:

'While waiting for radiologists to insert tubes into my body or for nurses to instruct me on wound management in the past, I tried to keep up a continual pattern of questions. The humiliation of bending over for a rectal exam, the discomfort of a gastrografin enema; before the creepy corporal proximity of exams, I queried those in charge — not to take my mind off my body, but instead to somehow embody them. How long have they worked here? Where did they come from? I wanted to remind us that their touching me meant that some part of me was touching them'.

Gubar also mentions shame from a different perspective. While she is writing about mourning for a 10-year-old boy named Seven Bridges who had a colostomy, and hanged himself because of being bullied, and subjected to racist insults by his classmates, she shared her experiences about having an ileostomy, and dealing with the leaks and smells. Humiliation and stigmatization are the signature of intolerance. It is an intolerance against being out of defined and imposed social norms, which defines the integrated and aestheticized bodies. She also mentions that because of her memoir 'Memoir of a Debulked Woman', she has been criticized by a reader, for causing harm to people who had the ostomy procedure. She defends herself by pointing out the potential damage that patients would be subjected to if they become silent about their emotions, like shame:

'Is shame so toxic an emotion that articulating it promotes it? Yes, I concede, shame may be contagious. In an effort to grapple with my shame, I express it and you, recognizing our commonality, catch it. Ought I therefore be ashamed of my shame and stifle its expressions? But silence can intensify shame, just as shame can intensify silence'(12).

Anger

What we should consider about anger, also with rejection, is that it can be the first reaction to an actual and sudden life event. As far as we understand from her journals, Audre Lorde experienced this sudden fierce anger against her breasts, her body. What she claims that she had felt, the betrayal, personalized her body and creates a dualism between her mind and her body:

'The year before, as I waited almost four weeks for my first biopsy, I had grown angry at my right breast because I felt as if it had in some unexpected way betrayed me, as if it had become already separate from me and had turned against me by creating this tumor which might be malignant. My beloved breast had suddenly departed from the rules we had agreed upon to function by all these years'.

The aggressiveness, and metastasis ability of cancer cells are affected by the microclimate of the cells. Lately, it is a major research field about immunotherapy-based cancer treatments, and one may find multiple articles about how to control the spread of malignant cells in a several

cancer journals: 'Cancer cells possess a unique ability to adapt to different environmental conditions, assuming different morphologies and migration characteristics to stay motile'. Alternatively 'The microenvironment influences the mode and dynamics of cancer cell migration'*(13).* What if the anger of a cancer patient can also spread? It is affected by the microclimate of the patient, and it can be controlled by the intense relations between these two. Who is a cancer patient's microclimate? For Lorde, it is the love of women that surrounds her, the community that she creates. Therefore, William Major in his article about Lorde's autopathography, precisely identifies the source of Lorde's anger, and discriminative approaches to cancer patients as I formerly mentioned:

"I believe that socially sanctioned prosthesis is merely another way of keeping women with breast cancer silent and separate from each other" Lorde unmasks the normative ideology of health by promoting her body's colour, deformity, and materiality… Shirley Neuman notes, "is that western cultures assume an analogy between mind, masculinity and culture, and body, femininity, and nature." Mastectomy, prosthesis and bra, are feminine norms about body and culture…"(14).

She strictly criticizes and refuses these "natural norms" that are imposed on women. One can consider these imposed roles on men, as rule-maker, and women, as rule-breaker. By patriarchy, a woman's anger is considered as a natural, feminine response of a rule-breaker, and should be rooted out. As a feminist scholar, Lorde expresses her anger, using violence against women:

"As women we have been taught to respond with a guilty twitch at any mention of the particulars of our own oppression, as if we are ultimately guilty of whatever has been done to us. The rape victim is accused of enticing the rapist. The battered wife is accused of having angered her husband. A mastectomy is not a guilty act that must be hidden in order for me to regain acceptance or protect the sensibilities of others."

Catherine Guthrie is another inspirational woman who refuses breast reconstruction aftera bilateral mastectomy. Her story also has subthemes about men's judgements about the female body, and the surgeon, with whom she discussed breast reconstruction, is the prototype of the indifferent and distant stranger, who is concerned about doing his job to correct the incorrect body.

"He sketched out how he would carve apart the largest muscle in my back. With one end of the muscle connected to its blood supply, the harvested flesh would be pulled through the empty socket on my chest and placed over a silicone implant. I saw a steak laid over a tennis ball.

"But isn't that muscle doing something?" I asked.

To which he answered, "You'll look normal in clothes; that's all most women want"(15).

As I see in both texts, anger is not easily identified and expressed, like fear or pain. However, I believe one can see one's own anger by reflective writing.

Conclusion

Healthcare providers could support each other to realize their emotional responses and gain appropriate control over them. We can remind ourselves that emotions are connected to our behaviors by mental roads that we are accustomed to acting on. We may always create new roads by close and attentive reading and reflective writing for the benefit of people who suffer.

On the other hand, life writing is a way of understanding, analyzing, and legitimating the emotions of both patients, and the people in the healthcare system that somehow intersect, and interact with patients, by creating a safe space for expression. When the author has the ability and courage to reflect on and communicate the experience with considerable narrative competence, this also stimulates a similar emotional response and understanding in the reader that can be related to aesthetic projection, and called empathy. Shared experience from different perspectives also contributes to the process of healing, engaging and connecting with oneself and the outer world again. In the texts I analyzed I have seen that all the authors create a new life that has a space for all the emotions accepted together, self-critically reorganized and reflectively expressed. I will finish with a concrete example of this from Audre Lorde's The Cancer Journals:

'I am 46 years living today and very pleased to be alive, very glad and very happy. Fear and pain and despair do not disappear. They only become slowly less and less important. Although sometimes I still long for a simple orderly life with a hunger sharp as that sudden vegetarian hunger for meat'(8).

While conducting the healthcare service, not only healthcare professionals' but also patients' perspectives should be included and acknowledged throughout the whole illness experience with all dimensions. Especially difficult and entangled situations that cancer patients face and represent via the illness narratives constructed as texts both provoke affective empathic understanding and meaning-making in the readers. This phenomenon, wich can either be named as artistic empathy or mutual creative and shared experience, is a new two-direction road established between a narrator/subject and an addressee -a patient and a physician, a patient and another patient- which seems to help the narrator/subject to reposition her identity as a cancer patient, and deal with traumas and difficult emotions, also provokes the addressee to give meaning to the experience of a stranger. Narrative medicine practices that create space, which patients and physicians encounter via texts, can open the doors, and prevent them from ignorance towards others' emotional status and different perspectives.

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THE MORAL FIELD OF ADVANCE DIRECTIVE AND ITS REGULATION IN BRAZIL

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Abstract: Despite more than 50 years of existence and their recognized importance, advance directives (ADs) are still the subject of doubts and criticism. The original defect, the instability of decisions, and the argument of personal identity are some of them. In Brazil, this instrument is not regulated by federal law, although Resolution No. 1995/2012 of the Federal Council of Medicine and Resolution No. 41/2018 of the Ministry of Health are in force, contributing to its implementation and to studies in this area. This article proposes to 1st) investigate some doubts and criticisms about ADs, as they challenge their moral authority; 2nd) highlight the repositioning of ADs in the moral field; 3rd) suggest this moral field as a starting point for bioethical investigations on their regulation in Brazil.

The approach was philosophical/bioethical (analytical), according to Aristotle's position in *Nicomachean Ethics* on the scope of ethical research.

It is concluded that ADs can be more robust and effective if their moral field is that of the circumstances, where the manifestation provides the person with moral choices and actions that operate in a grey area, allowing health professionals and their representatives to interpret their wishes according to each situation.

Keywords: bioethics, advance directives, personal autonomy

El campo moral de la directiva anticipada y su regulación en Brasil

Resumen: A pesar de sus más de 50 años de existencia y de su reconocida importancia, las voluntades anticipadas (VA) siguen siendo objeto de dudas y críticas. El defecto original, la inestabilidad de las decisiones y el argumento de la identidad personal son algunos de ellos. En Brasil, este instrumento no está regulado por la ley federal, aunque están vigentes la Resolución Nº 1995/2012 del Consejo Federal de Medicina y la Resolución Nº 41/2018 del Ministerio de Salud, lo que contribuye a su implementación y a los estudios en esta área. Este artículo propone: 1º) indagar algunas dudas y críticas sobre los EA, ya que desafían su autoridad moral; 2º) poner de relieve el reposicionamiento de las VA en el campo moral; 3º) sugerir este campo moral como punto de partida para las investigaciones bioéticas sobre su regulación en Brasil. El enfoque fue filosófico/bioético (analítico), de acuerdo con la posición de Aristóteles en la *Ética a Nicómaco* sobre el alcance de la investigación ética.

Se concluye que las VA pueden ser más robustas y efectivas si su campo moral es el de las circunstancias, donde la manifestación proporciona opciones y acciones morales que operan en una zona gris, permitiendo a los profesionales de la salud y a sus representantes interpretar los deseos del paciente de acuerdo con cada situación

Palabras clave: bioética, voluntades anticipadas; autonomía personal

O campo moral de diretivas antecipadas* e sua regulação no Brasil

Resumo: A despeito dos mais de 50 anos de existência e de sua reconhecida importância, as Diretivas antecipadas de vontade (DAV) ainda são objeto de dúvidas e críticas. O vício de origem, a instabilidade das decisões e o argumento da identidade pessoal são algumas delas. No Brasil, este instrumento não possui regulamentação na legislação federal, embora estejam em vigor a Resolução n.º 1995/2012 do Conselho Federal de Medicina e a Resolução n.º 41/2018 do Ministério da Saúde que contribuem para sua implantação e para estudos nesta área. Este artigo propõe 1º) investigar as principais críticas às DAV, considerando que estas desafiam sua autoridade moral; 2º) indicar o reposicionamento das DAV no campo moral; 3º) propor esse campo moral como ponto de partida das investigações bioéticas sobre sua regulamentação no Brasil. A abordagem foi filosófica/bioética (analítica), considerando a posição de Aristóteles na obra *Ética a Nicômaco* acerca do alcance da investigação ética.

Conclui-se que as DAV podem ser mais robustas e efetivas se seu campo moral for o das circunstâncias, quando a manifestação propicie à pessoa escolhas e ações morais que operam numa zona cinzenta, permitindo que profissionais de saúde e seu representante interpretem suas vontades de acordo com cada situação.

Palavras-chave: bioética, diretivas antecipadas, autonomia pessoal

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Introduction

Advances achieved in health care, and in life in general, during the 20th century, such as the development of medical techniques and interventions, as well as improvements in the quality of life overall, have increased the capacity to maintain and prolong human life, even in adverse situations. However, this has not necessarily meant benefit for patients in health care, as for some it may characterise the lengthening of suffering and death. There is an inevitable conflict between what is technically possible and what is humane, and ethically justifiable, requiring actions by professionals who will balance these two rival positions. In this conflict there is also the tension between the claim of respect for the patient's autonomy —and his self-determination— and that which is carried out for his benefit, for his well-being (his best interests)*(1-4)*. Such conflicts can still express two rival positions in dispute: the imperative recognition of the individual right to self-determination and the radical defence of human life*(4)*. ADs are both an expression and a consequence of these advances and conflicts*(2)*.

ADs emerged at the end of the 1960s, in the United States, from an article published by Kutner*(5)*. The discussion involved euthanasia and its legal impossibility. However, the law provided that no patient could be subjected to medical treatment without his consent, and had the right to refuse it, even if it was meant to prolong his life. This would anchor the possibility of refusing treatment in advance, should his medical situation become incurable, thus preventing him from recovering his cognitive capacities. Kutner named "Living will" the document that expresses the advanced wishes of people, capable of doing so, indicating their consent on the extent to which they agree with treatment*(5)*.

In the following decades, ADs developed and consolidated in the United States, mainly through the Patient Self-Determination Act, of 1990*(6)* - and have expanded around the world, becoming one of the emblems of patient autonomy recognition, regarding consent or refusal of treatment in medical care*(3)*. However, after more than 50 years, doubts and criticisms still remain about the nature, design, implementation and effectiveness of ADs. Some of them are: 1st) ADs original defect: assuming the possibility of controlling scenarios in future clinical care according to patient's wishes, is a false promise of ADs*(3,7)* or an act of faith, and not of will*(8)*. What does it mean to control the future?; 2nd) the instability of decisions: patient preferences must be stable in order to be "true" and this is an ambitious idea, because people reflect superficially on their choices before placing them in the "time capsule". Moreover, we have no experience deciding about dying*(9)*. New therapeutic options may change the patient's situation regarding ADs. What does it mean to control the process of dying?; 3rd) the personal identity argument would weaken the patient's moral authority, as the person who drew up his ADs would not be the same in the future, in cases of severe dementia, making their binding nature impossible. After all, should ADs be binding? In this sense, ADs would be ineffective and would promise more than they can deliver *(7,10)*. However, some of these arguments also apply to the informed consent practice in the medical setting, and are indied criticisms to the exercise of personal autonomy.

In Brazil, ADs are recent and still not well-known. They were introduced at the national level after Resolution No. 1,995/2012 of the Federal Council of Medicine*(11)*. In it, ADs are recognised as "the set of wishes, previously and expressly manifested by the patient, on the care and treatment he wants, or does not want, to receive at the moment when he is incapable of expressing, freely and autonomously, his will"*(11)*. Another important recent document has given greater visibility to ADs in Brazil: Resolution No. 41/2018, of the Ministry of Health, "which outlines ADs in the light of integrated continuous palliative care, within the scope of the public Brazilian health system (SUS – Sistema Único de Saúde/Single System of Health)"*(12)*.

Unlike other countries, such as Portugal, the United States, Uruguay, Argentina, Colombia, Spain, France and Italy, Brazil has no law regulating ADs, however, there is the Senate Draft Bill No. 149/2018*(13)* in progress in the National Congress, aiming to regulate them. The present article proposes, 1st) to investigate doubts and criticisms about ADs, considering that these challenge their moral authority; 2nd) to indicate the repositioning of ADs in the moral field, as stated by Aristotle in *Nicomachean Ethics(14),* on the scope of ethical research; 3rd) to propose this moral field as a starting point for bioethical investigations into their regulation and implementation in Brazil.

Advance directives (ADs): unrealistic expectations and false promises

Original defect: on the impossibility of predicting the future

Since their origin, controversies have surrounded and characterised ADs. One of them was that of predicting and controlling future scenarios in end-of-life medical care. The possibility of controlling scenarios in future clinical care according to patients' wishes has proved to be a false promise of ADs*(7)*. The belief that we can control our future, without knowing the details of our situation, is problematic. What we choose as ends is always, to a greater or lesser degree, limited by the context, in other words, by what our biopsychosocial circumstances allow*(15)*. However, given the impossibility of predicting the future, ADs can be supported by two perspectives: 1) as a precautionary measure; 2) drawn up in the context of Advance Care Planning (ACP)*(4)*. In short: The precautionary principle is adopted when actions must be taken without certainty, but supported by strong evidence of risks that the person wants to avoid; the moral authority of ADs is strengthened under the umbrella of ACP.

Furthermore, ADs are also vague and nebulous: lack of knowledge about future clinical situations prevented precise elaboration of ADs*(4)*, and these generally provided little information about what quality of life meant for patients*(16)*, since the person who wrote their ADs could be in a completely different situation in the future, and the generic nature and hypothetical content of the ADs may not reflect that person's current wishes, values and preferences*(4)*. Indeed, if the specific purpose of ADs is their application in medical care, and they are generic and non-specific in nature, their promises to guide medical practice fail. Moreover, there is a disproportion between precision and prediction about what is determined in these documents as well as the circumstances in which the concrete event takes place*(4)*. Although they are generic in nature and have a hypothetical content, ADs are requested for concrete and specific situations, i.e. they are always requested in the present and this limits their reach considerably*(17)*.

ADs generally fail when trying to determine medical procedures without taking into account the description of applicable scenarios*(18)*. The patient controlling decisions at the end of life is an empty promise of ADs, as they do not take into account the asymmetrical power relationship in the clinical decision-making process. Patients and their families are in a situation of emotional fragility and their surrogate decision-maker will not be in control of the situation as it is the physicians who determine treatment options as well as when ADs will be invoked. In this sense, ADs are empty and do not produce the expected results*(19)*. It should also be noted that it is reasonable to admit the difficulty of thinking about ADs, because there is no reality to support it. The absence of experience about future complications in a person's health makes the process by which one would want to anticipate feelings on the basis of a non-existent reality empty and useless*(20)*. Thus, the argument of medical practice being guided virtually by patient autonomy would not justify the need for ADs*(3)*. This is the reason why some countries made ADs legally binding, so that physicians are compelled to use an AD. Meaning that the burden of proof for its refusal is on the side of the physician that is subject to liability for this practice.

One of the central problems of ADs is the lack of synchrony between the person's early consent or refusal and the physicians' decision and action on necessary treatment. The uncertainties are many in dealing with something that is not currently known*(4)*. What does it mean to express consent about what we do not know? If informed consent is one of the expressions of people's autonomy and self-determination, then ADs do not satisfactorily fulfil what they promise. This is their clearest original defect. We do not control the future. There is always something that escapes us, the circumstances in which our decisions take place. ADs operate in the present time, and as a tool for future medical care have been shown to be ineffective*(17,18)*. This is also a question regarding the normal practice of informed consent and to avoid this problem there should be a clear and extensive information of the patient/person before writing a living will. However, it should be noted that the patient's legal representative (surrogate decision-maker), as someone who knows the patient's wishes, values and preferences, and the dialogue involving the family in the Advance Care Planning (ACP) process may reduce the ineffectiveness of ADs, when faced with something uncertain. At the end of the next section, we will point out some considerations on ACP.

AD' moral authority and its binding character: the personal identity argument

The moral authority of ADs, its required value, is necessarily associated with their binding character. The wishes, values and preferences of the patient expressed in ADs must be respected in the future, and they must meet at least two criteria: they must not violate the laws of the country, and the person who draws them up must be the same person who will have them respected in the future. One person cannot prepare another person's ADs because this would nullify the expression of the autonomy and self-determination of the person who expresses in advance which medical care is desired or not, in the future*(21,22)*.

Thus, without compliance with these criteria, ADs become useless. Without their binding nature, they become empty. Despite their limited scope in clinical care, as they do not encompass all cases, it is worth considering the performance of ADs in the case of people with severe dementia. If it is correct to state that ADs were created to extend and guarantee people's autonomy in future medical decisions, even when they are no longer autonomous*(3)*, how can we sustain their moral authority? How can we sustain their binding character? If people with severe dementia can have their personal identity altered, then the second criterion is not met, as the person who drew up their ADs is no longer the same person who will have them fulfilled. There is a person prior to cognitive decline and there is another person with severe dementia. But it can also be claimed that it is the same person with profound changes in personality and even in capacity. Meaning that if a person with dementia is incompetent to decide ADs may be clinically useful and legally binding.

The personal identity argument is the strongest criticism of the moral authority of ADs under dementia disorders. It is an old and prevalent criticism*(3,21,23,24)*, and is based on the research of Parfit on psychological continuity, but this will not be addressed here(*25)*. Even though ADs have taken distinctive contours over more than half a century, the personal identity argument is a problem for ADs claims. We will set out this controversy by confronting two rival positions: 1st) the personal identity argument weakens the moral authority of ADs; 2nd) the personal identity argument does not undermine the moral authority of ADs.

The first position is defended by means of three brief considerations *(3,4,24)*:

1.1) Tonelli argues that ADs, for incompetent patients with cognitive decline, have little value because the idea of extending autonomy through them fails. Generally, human beings change their interests throughout life, and with incompetent patients the same thing happens. However, what is lost here is the ability to make decisions, albeit with new values and preferences. He points out further that, claiming that advance decisions about medical care should necessarily be applied even when contrary to the clearest interests of a person who has lost the capacity to make decisions, is a problem, binding that person who drafted their own ADs to this now incompetent person. The illustration he uses is significant: a "pleasantly" mentally ill patient, a mathematician retired due to Alzheimer's disease, expresses his wishes in writing, before the diagnosis, stating that he does not wish to live without his cognitive abilities. Now, faced with his illness, the mathematician seems to carry out his daily activities with satisfaction and responds with a positive sign when asked if he is happy. His interests have inevitably changed, as has his personality, and those who knew him previously find in him only traces of his former self. To fulfil the wishes expressed in the ADs, according to Tonelli, the new person into which the mathematician has become is ignored, and his present interests will be conditioned to those of a non-existent person*(3)*. However, it can be argued that the meaning of incompetency in decision-making is, precisely, the inability to make choices. So to sustain the first position it must be proved that a patient with advanced dementia has really new values and preferences, because in this case he would have to be considered competent and not incompetent.

1.2) Walsh considers that the moral authority of ADs cannot have a significant influence on medical decisions. The justification starts from two rival positions on the binding character of ADs. The first, a view recognised in philosophical literature, holds that ADs are binding; the second, a widely accepted view in clinical practice, expresses the resistance of physicians to comply with them if they are at odds with the mentally ill patient's current well-being and preferences. Walsh argues that Dworkin's conception, based on the idea that a person's critical interests are stable during their life and that decisions about the end of their life rest exclusively with him, does not justify their strong moral authority. Walsh will defend the second position. There are two reasons: clinical practice at odds with them idea, as noted above, and for disregarding the experiences of cognitive transformations in people with dementia, that imply legitimate changes in their desires, values and preferences. These would be considered to the detriment of those listed in ADs. This would be enough to set back the moral authority of ADs, giving them a weak moral authority, i.e. without the binding character. Walsh cites case study to illustrate these rival positions. Mrs. Black, aged 80, was diagnosed with progressing intermediate dementia. In many situations, she struggled to remember the names and faces of family members. At the old people's home, however, she was recognised by the nurses as a very happy lady, enjoying her daily activities. During this period, Mrs. Black developed a serious bacterial infection. She had an AD which stipulated refusal of medical treatment to prolong her life, if she suffered from an illness that made her incapable of recognising her family members. She would not wish to receive any medical treatment to prolong her life. Her son insisted on compliance with his mother's AD, and soon after she died. The entire medical team was devastated*(24)*. But, again,

1.3) Vergallo pointed out that the generic nature and hypothetical contents of ADs make their binding nature unfeasible, because they do not express, in a specific way, the wishes and preferences of the person. One effect of this is the restriction of their scope. ADs will only be effective in limited clinical situations, such as medical decisions involving patients in a persistent or permanent state of unconsciousness, as well as in patients in a persistent and permanent vegetative state, or with cognitive decline that degenerates decision making skills. Another difficulty that makes the binding nature of ADs unviable is their excessively strict and deterministic application, since they force physicians to comply with the wishes of patients regardless of their content. To reduce the limitations on ADs, increase their effectiveness, and avoid their generic and vague nature, according to Vergallo, it is appropriate to move them to the moment the disease starts, especially dementias, i.e. to move ADs to Advance Care Planning (ACP). Here, there is a certain degree of guarantee in relation to the fulfilment of the patients' wishes already in the context of clinical care, with safer predictions because the patient knows the diagnosis, facilitating the therapeutic relationship. Thus, according to the author, the binding nature of ADs is not sustained if restricted to the generic ADs. When associated with the ACP, their effectiveness will be enhanced*(4)*.

The second position is defended in three considerations*(23,26,27)*:

2.1) For Porteri, the personal identity argument looks attractive from a theoretical perspective, but does not stand the test of reality. In real life, people do not wish to live in the future with dementia. It is not about fear of someone else's future, but their own. It is not the possibility of a new person in the future that terrifies them, personality changes, new desires, values and preferences, but that potential changes are about themselves and not about a new person in the future. Body identity is sufficient for personal identity as it is for psychological continuity. However, there are conflicting interests of patients with severe dementia, the ones from before and after dementia. What mattered before, may not matter after. The way out of this conflict is the prevalence of the patient's critical interests, which are those prior to their cognitive decline. In this sense, ADs are binding, independent of the 'new preferences', as they give voice to the wishes, values and preferences of people/patients at that present time. They express the way the patients perceive the world and themselves, and are above the preferences and values of physicians and family members. Thus, not fulfilling the ADs of a person with dementia would be the same as never considering them competent and, therefore, unable to decide for themselves about their life*(23)*.

2.2) Jongsma objects to the idea that people with dementia experience cognitive transformation and, therefore, new values, desires and preferences will emerge, in collision with previous ones. The consequence of this, at least, is that the moral authority of ADs is debatable to the extent that previous wishes, values and preferences cannot override current ones - of the person with dementia. For Jongsma, people with dementia progressively lose cognitive capacity, and in their decline are unable to make some decisions for themselves. Behavioural change is not a necessary expression of new preferences and values. It is not plausible that people with cognitive decline would recognize their previous values and preferences, and consider that the current ones should override those. In this sense, ADs have moral authority because people can craft them in such a way as to ensure that their current values, desires and preferences, thoughtfully displayed, may not be possible to live up to as a result of cognitive decline, and they wish these to override future ones arising from dementia. People in this condition progressively lose the capacity to make reasonable choices for themselves. People who design their ADs foreseeing future cognitive decline, and unable to live according to their preferences, attest that they will still be treated according to their carefully thought-out values and preferences, and not according to future values and preferences, a consequence of cognitive decline. Even in the face of uncertainty, of the risks of the decision taken (not remembering previous decisions regarding ADs, and having new preferences and values with cognitive decline), it should not be changed, even in the face of a new situation, such as new preferences and values*(26)*.

2.3) Despite agreeing that changing preferences in progressive dementia may weaken the moral authority of ADs, Menzel considers that this does not destroy them. First, because the expectation of people during progressive dementia to constitute themselves as other selves is irrelevant, as what matters for people who elaborate ADs is not to live too long in a deteriorating way. These patients do not wish to live that way, as an undignified end of life. However, if on the one hand he considers the need for compliance with the ADs of the previously capable person, by their proxies and carers, on the other he recognises the incompetent person is now someone with some value to their own life, finding some subjective value in life. It is, undeniably, a difficult situation, as it maintains a dilemma. Menzel proposes a partial way out: not infrequently, people with severe dementia lack the ability to anticipate tomorrow and remember yesterday. The value of life that remains is that of the moments lived today, just for living them. There is no sense here of the value of people's lives in anticipating tomorrow and remembering yesterday. Still, even if the subjective value for that person whose life is "is not", its value is important. In any case, it considers that the controversy over personal identity does not affect the moral authority of ADs, that is, their binding character*(27)*.

As noted earlier, the personal identity argument seems to be the central philosophical issue about the moral authority of ADs*(21,24,28)*. If incompetent patients change their preferences, wishes and values, as a result of cognitive decline under severe dementia illness, what preferences, wishes and values will be valid? Walsh pointed out the same problem, considering two rival positions, the philosophical one, which logically defends the binding nature of ADs, and clinical practice, which often resists complying with ADs in situations involving dementia*(24)*. The specificity of ADs in the context of people with severe dementia should be emphasised, as patients in this situation may be able to express, in some way, emotions, preferences, wishes and values. However, signs of wellbeing in these patients may not express the realisation of a will to live*(29)*. Thus, which decisions will prevail? Those of the competent person who prepared the ADs, or the decision of the now incompetent patient who expresses other values, wishes and preferences? Moreover, there is another aspect to be considered. If there are two different persons, the one before the illness and the current one, then one of the criteria is not met, in order to guarantee the moral authority of the ADs, which consists in the person who drew them up to be the same person who will have them fulfilled in the future. Such controversies seem to imply a weakening of the moral authority of ADs, since its binding character, which sustains it, is in doubt.

There is, it seems, a dilemma, as both alternatives are unsatisfactory. If ADs are binding on people with dementia, then their moral authority is guaranteed, but it moves away from the proper contexts of clinical care. If, on the other hand, ADs are not binding but indicative, then the moral authority of ADs loses force, and decisions about whether or not to comply with them will bind, more strongly, in the best interests of the patient in the context of the actual circumstances. However, there are also, at least, two possible solutions to this apparent dilemma. A well-known solution is to define through law whether or not ADs, in a given country, are to be legally binding, as is the case in several places, such as the Netherlands, Portugal, Belgium, Denmark and the United States (legally binding) and Germany, Switzerland and Norway (legally non-binding)*(24)*. The other is to face the philosophical difficulties and those of clinical practice that ADs expose.

Some considerations on Advance directives (ADs) and Advance Care Planning (ACP)

ACP is defined as "a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care"*(30:826)*. ACP ideally begins with conversations involving patient, family and the clinical care team about the preferences and objectives of that care*(31)* and medical care no longer focuses on defining specific future treatments, but how different states of health are in accordance with patients' preferences and values*(32)*. The primary idea of ADs, as an event, summarised as the production of a document, is abandoned in order to incorporate the sense of process, as is ACP*(17)*. The shifting of ADs as part of the ACP process redefines their role and mitigates some of the criticisms and doubts about them.

One of the acknowledged advances in this shift is the fact that ACP provides effectiveness to ADs*(33)*, because by starting with the diagnosis of the disease the ACP process will be based on proximate reality, removing the vagueness and generality of ADs*(34)*. Moreover, it does not solely focus on end-of-life care*(31)*.

In any case, part of the criticism and doubts that still persist about ADs can be faced, perhaps, from the delineation of its moral field. To this end, we will resort, in general lines, to aspects of Aristotle's ethical investigation in *Nicomachean Ethics(14)*.

The moral field of ADs: resorting to Aristotle's ethical research

Aristotle pointed out, at the beginning of *Nicomachean Ethics*, that the good and just actions, the object of investigation of "political science" (practical sciences - politics and ethics), seem too vague and varied so as to consider their existence by convention rather than by nature*(14:I 31094b-14-17)*. This is due to the consideration that human activities, such as choices and actions, aim at some good (an end) and the ultimate good to which all things tend is *eudaimonia* (happiness, good living, good action), but, about the meaning of *eudaimonia*, there are many conflicting opinions*(14:I 1-2 1094a1-23;4 1095a17-21)*. If wealth and courage are a good, considers Aristotle, there are people who have been lost because of them*(14:I 3 1094b-14-16)*. Ethical enquiry inhabits a grey area because the nature of human actions is essentially uneven. If this is correct, it is not promising to investigate moral questions, such as the meaning of "dignified death" or "dying with dignity," expecting verifiable conclusions.

In this sense, the moral field of the practical 'sciences' - politics, ethics and household administration - has its own identity, and the truth in ethical research is given in general terms*(14:I 3 1094b19-21)*. For Zingano, it is a common understanding that Aristotle recognizes that ethical enquiry supports generalisations of the "all too often" type, but these do not compare to the generalisations of the natural sciences of the "most often" type. The basic register of moral language is particular actions in specific circumstances. In them, human choices and actions operate. Although Aristotle admits strict universalizations, absolute prohibitions, such as not committing murder, these are few*(35)*.

The scope of ethical investigation is that of indeterminacy, according to Aristotle. Therefore, truth in ethics is by approximation, because unlike mathematics, the object of its investigation is human action, and this occurs in circumstances whose moral value is indeterminate. Ethical enquiry (moral reasoning) in Aristotle, does not constitute a prescription of principles and procedures to be followed for right action. The agent is, in a sense, alone in the face of indeterminate circumstances, and it is not possible to assess the moral value of these. Circumstances carry their own moral value and the agent will be faced with them, "here and now", to determine their moral value*(35)*. Similarly, ADs occupy this position of indeterminacy. Although wishes (desires, values and preferences) regarding medical care are expressed in advance for future fulfilment, ADs become effective in the present time, in a concrete and specific situation, and submitted to the clinical context*(32)*.

It seems contradictory to demand from ADs stability in human choices and actions if these always operate in circumstances, in contingency. The moral field is not a field of certainty, of stability. The problem of the inaccuracy of ethics is not only fixed in the limitation of what practical research intends, an approximate truth, but also in the very nature of human actions, unstable and imprecise*(36)*.

Repositioning ADs within the moral field of which Aristotle's ethical investigation recognises and addresses does not diminish their moral authority, it merely establishes their limits and scope in practical situations. These are not only defined according to the nature of ADs, but mainly because it belongs to the practical domain, the moral field, addressed by Aristotle. The unreal and real expectations in relation to ADs depend not only on these, but also on the place it occupies, and this does not seem to be that of the natural sciences, another domain, but the moral field with its specificities and properties. Therefore, the differences between the domains of ethics and another area of knowledge is not one of degree, but of pattern, for these are distinct*(37)*.

There is no reason to condition the effectiveness of ADs solely on scientific demands and decision-making models in end-of-life medical care. They must also be evaluated within their own field, within the practical domain, and survive the scrutiny of clinical contexts, circumstances and contingencies. ADs as a tool to identify treatment preferences in a hypothetical situation, without the concrete disease scenario, are ineffective*(38)*.

ADs are not just a tool to control death and dying, nor are they an expression of our autonomy. It is also about the ontological impossibility of mastering the contingent, uncertain world like ours. Perhaps, because of this, it is not an exaggeration to consider that some of the criticisms to ADs exceed what they can offer, such as not being able to address the instability of human decisions according to hypothetical future scenarios. It is exactly because we do not master the contingent world, even more so the future, that the possibility of choices and actions in the moral sphere are open to us. In a certain sense, the effectiveness of ADs is restricted, paradoxically, to the denial of its binding character, the difficulty of a stability of decisions. Pursuing it, imposes the risk of failure, perhaps the same risk of having to deal, as Wiggins pointed out, with the torments of thought, with the torments of the past, of feelings, and of understanding, which can involve our choices and actions without appeal to normative ethical models*(39)* and, according to Haesen and Shaw, the torments of accepting and facing one's own mortality, not only under the pretext of controlling living conditions, but also of distancing oneself from unrealistic expectations about one's own wishes regarding medical care*(40)*.

Regulation of ADs in Brazil

In Brazil, although applied, ADs are not regulated. Resolution No. 1995/2012 of the Federal Council of Medicine, which provides for ADs, is the reference document for reflections on ADs*(11)*. These were recognised as "a set of wishes, previously and expressly manifested by the patient, on the care and treatment he wants, or does not want, to receive at the moment when he is incapable of expressing, freely and autonomously, his will"*(11:article 1)*. The Resolution defined that physicians and doctors "take into consideration" the patients' ADs or of their legal representative, not attributing them a binding character. Another Resolution, No. 41/2018, of the Brazilian Ministry of Health, establishes the availability of ADs for patients in Palliative Care throughout Brazil*(12)*. It is the first legislation of the Brazilian executive power on the subject and shows an extraordinary advance in respect to the regulation of ADs in the country, although limited to patients in Palliative Care. In addition to these two resolutions, there is also the Federal Senate Draft Bill No. 149/2018, currently pending in the National Congress*(13)*, aimed at regulating them, and some observations should be made about it.

With regard to draft Bill No. 149/2018, three aspects stand out. 1st) ADs are specifically intended for end-of-life medical care; 2nd) focuses on the preparation of an ADs document to be expressed by means of a public deed; 3rd) contemplates the binding character, but admits exceptions*(13)*. On this third aspect, as pointed out earlier, making ADs binding, or informative, by law does not eliminate the ethical difficulties, especially those directed at people with dementia. Regarding the first and second aspects, conditioning the registration of ADs through public deed and on end-of-life medical care could limit the scope and effectiveness of ADs. The text of the Draft Bill, as it currently stands, may also imprison ADs to one event, that of only drafting a generic and abstract document.

Regarding the knowledge and understanding of ADs in Brazil, studies suggest the existence of the challenge of making, incisively, ADs more known and debated among the population, and among students and health care professionals, as well as the limits of its application*(41-47)*; as to the acceptance of ADs, other studies suggest that they are widely accepted from the moment of their knowledge, both by patients and relatives, as well as by professionals and students in terms of respecting and complying with them*(48-50)*. However, it should be noted that these studies still focus on the knowledge, preparation and fulfilment of ADs, a difficulty to be overcome perhaps over time, as there seems to be an excessive valuing of documents in ADs, or in the determination of models, in detriment of the process involving health care. An indication of this can be found in publications such as those of Dadalto*(51),* Dadalto and Carvalho*(52)*, and Pittelli et al*(53)*.

Difficulties in access to health care and the absence of health literacy among patients, as well as cultural diversity*(34)*, in a country like Brazil, with its continental extension, should be considered when trying to regulate and implement ADs in Brazil. Perhaps the most appropriate way to implement ADs in Brazil is to regulate it by recognising and addressing its limitations and scope. Strategies and documents for its elaboration are important as long as they do not incorporate unrealistic expectations and false promises. The binding or non-binding nature of ADs should be defined in their regulations. As we have noted, ADs lose their identity without their binding nature, but they gain in effectiveness in clinical practice if the circumstances in which they will be fulfilled are recognised. One possible solution is to anchor ADs in the territory of advance care planning (ACP), where patient preferences and values can be recognised and welcomed without much conflict, as they deal with the knowledge of diagnosed illness and not the vagueness and abstraction of future treatments by people who do not live the concrete situation.

Concluding remarks

It is understandable, in some situations, the need for the watchmaker to adjust the clock without stopping it, just as it is reasonable in Brazil to regulate ADs, adjusting them to their current application, considering and recognising its moral field, its limitations and its reach. Its regulation will certainly bring more security to its implementation, but it will not completely keep us away from the doubts and criticisms that still lie on them - philosophical, ethical and bioethical questions.

Thus, the necessary adjustments to the ADs for their implementation in Brazil could perhaps follow this brief outline: 1) ADs do not apply to all cases, as their scope is limited by their moral field; 2) the binding nature of ADs is the clearest expression of their moral authority, but may, as a consequence, be less effective; 3) ADs document models are important tools for knowledge and understanding of the meaning of clinical decisions about the future and not just legally recognized documents; 4) Education on ADs for health care professionals, the population, institutions, among others, as death and dying are still taboo.

As Aristotle pointed out in *Nicomachean Ethics(14)*, ethical enquiry is that of the practical domain, the realm of the indeterminate, of circumstances, where our choices and actions operate, and truth in ethics is by approximation. In this moral field, perhaps the ADs can be more robust and effective, in the efforts to regulate them in Brazil, when the manifestation provides the person with moral choices and actions that operate in a grey area, allowing healthcare professionals and their representatives to interpret their wishes according to each situation.

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ETHICAL REVIEW ON THE IMPACT OF WORK STRESS ON EMPLOYEE DEPRESSION

Qihan Zhang[1], Jinzi Liu[2], Ke Tan[3]

Abstract: Introduction: The study is grounded in the Stress-Stressor-Health Outcome Model and the Conservation of Resources (COR) theory, by examining the mechanisms through which personal factors, such as psychological capital and work burnout, influence the relationship between work stress and employee depression, aims to provide valuable insights and guidance for future corporate psychological support services.

Methods: A total of 1,312 employees participated in an online survey, completing a self-report questionnaire that included the Work Stress Questionnaire, the Patient Health Questionnaire-9, the Psychological Capital Questionnaire, and the Job Burnout Questionnaire. A chain mediation model was employed to explore the relationships among these four variables.

Results: The results revealed that: (1) 13.6% of employees suffer from moderate or severe depression; (2) Job burnout mediates the relationship between job stress and employee depression, amplifying the effect of job stress on depression. (3) Psychological capital and job burnout serve as a chain mediator in the relationship between work stress and employee depression.

Conclusion: This suggests that under work stress, higher levels of job burnout are associated with a greater risk of depression; improving psychological capital can buffer job burnout and reduce the risk of depression.

Key words: work stress, psychological capital, job burnout, employee depression

Revisión ética sobre el impacto del estrés laboral en la depresión de los empleados

Resumen: Introducción: El estudio se basa en el Modelo de Resultados Estrés-Estrés-Salud y la teoría de la Conservación de Recursos (COR), al examinar los mecanismos a través de los cuales los factores personales, como el capital psicológico y el agotamiento laboral, influyen en la relación entre el estrés laboral y la depresión de los empleados, tiene como objetivo proporcionar información valiosa y orientación para futuros servicios de apoyo psicológico corporativo.

Métodos: Un total de 1.312 empleados participaron en una encuesta en línea, completando un cuestionario de autoinforme que incluía el Cuestionario de Estrés Laboral, el Cuestionario de Salud del Paciente-9, el Cuestionario de Capital Psicológico y el Cuestionario de Burnout Laboral. Se empleó un modelo de mediación en cadena para explorar las relaciones entre estas cuatro variables.

Resultados: Los resultados revelaron que: (1) el 13,6% de los empleados sufre de depresión moderada o severa; (2) El agotamiento laboral media la relación entre el estrés laboral y la depresión de los empleados, amplificando el efecto del estrés laboral sobre la depresión. (3) El capital psicológico y el agotamiento laboral sirven como mediador en cadena en la relación entre el estrés laboral y la depresión de los empleados.

Conclusión: Esto sugiere que bajo estrés laboral, los niveles más altos de burnout laboral se asocian con un mayor riesgo de depresión; Mejorar el capital psicológico puede amortiguar el agotamiento laboral y reducir el riesgo de depresión.

Palabras clave: estrés laboral, capital psicológico, burnout laboral, depresión de los empleados

Revisão ética do impacto do estresse no trabalho na depressão de funcionários

Resumo: Introdução: O estudo é fundamentado no Modelo Estresse-Estressor-Desfecho em Saúde e na teoria da Conservação de Recursos (COR), ao examinar os mecanismos através dos quais fatores pessoais, tais como capital psicológico e estafa no trabalho, influenciam a relação entre estresse no trabalho e depressão de funcionários, objetivando fornecer entendimentos valiosos e diretivas para serviços de apoio psicológico futuros.

Método: Um total de 1312 funcionários participaram em um levantamento online, completando um questionário de autorelato que incluía o Questionário de Estresse no Trabalho, o Questionário de Saúde do Paciente-9, o Questionário de Capital Psicológico e o Questionário de Estafa Profissional. Um modelo de mediação em cadeia foi empregado para explorar as relações entre essas quatro variáveis.

Resultados: Os resultados revelaram que (1) 13,6% dos funcionários sofrem de depressão moderada ou grave; (2) Estafa profissional medeia a relação entre estresse profissional e depressão de funcionários, ampliando o efeito do estresse profissional na depressão, (3) Capital psicológico e estafa profissional servem como um mediador de cadeia na relação entre estresse no trabalho e depressão de funcionários.

Conclusão: Isso sugere que sob estresse no trabalho, níveis mais altos de estafa profissional estão associados com um maior risco de depressão; melhorar o capital psicológico pode amortecer a estafa profissional e reduzir o risco de depressão.

Palavras-chave: estresse no trabalho, capital psicológico, estafa profissional, depressão de funcionários

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1 Introduction

Depression is regarded as the leading mental health issue among employees in both enterprises and public institutions*(1-3)*. According to *the Ninth Survey of Chinese Workers(4)*, the total workforce in China is approximately 402 million, representing a key force driving the prosperity and development of various sectors in China. However, with social transformation, the acceleration of life and work rhythms, changes in production models and management systems, as well as heightened competition, mental health issues among Chinese workers have become increasingly prominent. Numerous studies have shown that the prevalence of depression among workers is generally higher than 30%*(2,5-9)*. Although an increasing number of companies are beginning to pay attention to employee depression, many still lack dedicated mental health services for their staff. Some companies that have implemented such services struggle with insufficient funding and budget allocation, which leads to limitations in service coverage, accessibility, and effectiveness. Between 1990 and 2019, the number of people diagnosed with depression in China increased from 31.3 million to 41 million, reflecting a 31% growth in cases*(10)*. This highlights the urgent need to address and improve the mental health of the workforce.

1.1 The Impact of Work Stress on Employee Depression

With the rapid development of the social economy and the growing complexity of the work environment, work-related stress has become one of the most prevalent psychological stressors in modern occupational groups*(11)*. Work stress refers to the pressure employees experience due to heavy workloads, role changes, overwhelming job responsibilities, or other work-related factors*(12)*. Previous research has shown that chronic work stress increases the risk of depression in individuals*(7,13-20)*.The effort-return imbalance model suggests that when employees experience high effort but low reward over an extended period, their stress significantly increases, thereby raising the risk of depression*(21)*. Similarly, the demand-control model argues that when job demands are high (e.g., heavy workload and tight deadlines) and decision-making autonomy is low (e.g., lack of control), employees are likely to experience significant stress. Prolonged psychological pressure under such conditions can lead to depression*(22)*. Therefore, excessive work stress can directly impact employee depression.

In today's society, the widespread use of information technology and digital tools has blurred the "work-life boundaries" for employees. Coupled with the uncertainties of globalization and market dynamics, companies often require employees to take on more tasks and responsibilities in order to enhance productivity and maintain competitive advantage. Faced with the dilemma of "reducing work stress to alleviate employee depression" versus "increasing work stress to boost corporate competitiveness", companies typically opt for the latter. However, some studies suggest that the relationship between work stress and employee depression is not direct, but is mediated or moderated by various factors. For instance, some studies have found that certain sources of work stress*(23)*, such as long working hours and workplace conflict*(24)*, are not associated with depressive symptoms. A meta-analysis by Virtanen et al.*(25)* on long working hours and depression also revealed significant heterogeneity in the relationship, which varied by survey area. Some individuals, despite facing high levels of work stress, employ positive coping strategies that do not negatively impact their physical and mental health*(26)*. Consequently, the level of depression among employees may be more closely linked to individual factors than to objective work stress. Since most companies are unable to reduce the objective work-related stress, they can instead focus on addressing employees' psychological factors by providing support services.

1.2 The Mediating Role of Job Burnout

Several studies have shown that job burnout plays a significant role in the relationship between work stress and employee depression*(20,27-29)*. Job burnout is a psychological response to chronic work stress, characterized by emotional exhaustion, depersonalization, and a diminished sense of personal accomplishment*(30)*. Work stress is the primary cause of job burnout, and there is a significant positive correlation between the two*(31-37)*.Job burnout is also a positive predictor of depression, the higher the level of burnout, the greater the likelihood of developing depression*(20,38,39)*. The Stress-Stressor-Health Outcome Model*(40)* also emphasizes that various workplace stressors are key triggers of employees' psychological stress responses. If these psychological stress responses are not alleviated over time, they will further impact the individual's health, including mental health (e.g. depression), physical health (e.g. cardiovascular diseases) and behavioral performance (e.g. reduced work efficiency and increased turnover intentions). This model suggests that stress and health outcomes are not directly related, but rather mediated by psychological stress response. Therefore, based on this theory and related studies, this research proposes Hypothesis 1: The direct effect of work stress on depression may be relatively weak, but the influence of work stress on depression will be amplified through the mediating effect of job burnout, as shown in Figure 1.

1.3 The Mediating Role of Psychological Capital

Psychological capital refers to the positive psychological states exhibited by individuals during development, and the positive influence of these states have on individual behavior. It is a psychological resource that can be developed and enhanced, encompassing four dimensions: self-efficacy, hope, optimism and resilience*(41)*. The studies have demonstrated a significant negative correlation between psychological capital and job stress*(42-44)*, and it can significantly predict lower individual depression levels*(10,43,45-47)*. Work stress increases the occurrence of negative emotions by depleting psychological capital. As a protective factor for mental health, psychological capital mitigates the risk of depression by counteracting the negative emotions induced by work stress*(48)*. Therefore, psychological capital serves as a mediator in the relationship between job stress on depression.

However, unless severe negative events serve as stressors, the negative emotions exacerbated by the decline in psychological capital due to daily work stress do not necessarily lead to depression. Negative emotions only trigger depression after accumulating to a certain level, leading to psychological exhaustion (a quantitative to qualitative change, *42*). The studies have highlighted that job burnout is a precursor to depression*(49)*. The Conservation of Resources (COR) theory posits that psychological capital, as a psychological resource, can help individual cope with stress, achieve goals, or protect themselves from threats. High job stress depletes psychological capital, and the ongoing depletion of psychological capital is a key driver of job burnout. After resource exhaustion, individuals will lack coping abilities, feel out of control and helpless, leading to job burnout, which is an important cause of depression, ultimately increasing the risk of depression*(50)*. Therefore, psychological capital is more likely to mediate the relationship between work stress and job burnout, rather than between work stress and depression. Based on the above discussion, we propose Hypothesis 2: Psychological capital is an antecedent variable of job burnout, and both psychological capital and job burnout jointly mediate the effect of work stress on employee depression, as illustrated in Figure 1.

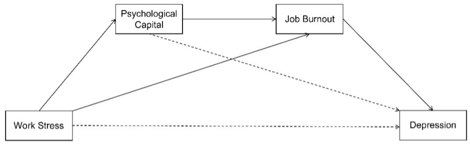


Figure 1: Hypothetical Model of Variable Relationships

To test the above hypotheses, this study utilized the Work Stress Questionnaire, the Patient Health Questionnaire-9 (PHQ-9), the Psychological Capital Questionnaire, and the Job Burnout Questionnaire to collect and analyze data from 1,312 employees across government agencies, enterprises, and public institutions in Tianjin. If the above assumption holds true, companies can focus their mental health services on enhancing employees' psychological capital and alleviating work burnout, thereby minimizing the negative impact of work stress on employee depression.

2 Methods

2.1 Participants

This study collected data online from employees of enterprises and institutions in Tianjin using the Questionnaire Star platform (https://www.wjx.cn/), resulting in a total of 1,312 questionnaires. After removing invalid questionnaires based on lie detection questions (for example, "please choose 'basically in line' for this question"), 1026 valid questionnaires were retained, yielding an effective recovery rate of 78.20%. The participants' ages ranged from 18 to 62 years, with a mean age of 37.29 ± 8.43 and 35.10% were men. Additional demographic information is provided in Table 1.

2.2 Tools

2.2.1 Work Stress Questionnaire

This study employed a questionnaire consisting of a three-item scale developed by Motowidlo, Packard, and Manning*(51)*"given":"John S."},{"family":"Manning","given":"Michael R."}],"issued":{"date-parts":[["1986"]]}}],"schema":"https://github.com/citation-style-language/schema/raw/master/csl-citation.json"} to assess participants' work stress. This questionnaire has been widely used to assess employee work stress, owing to its strong reliability and validity. The questionnaire employs a 5-point Likert scale, where "1" indicates strong disagreement and "5" indicates strong agreement, with higher scores reflecting greater agreement. In this study, the Cronbach's alpha coefficient for the questionnaire was 0.86; the structural validity measures were: X^2/df=6.69, RMSEA=0.07, SRMR=0.08, CFI=1.00, TLI=0.99, with standardized factor loadings ranging from 0.68 to 0.930, indicating good reliability and validity.

2.2.2 Patient Health Questionnaire-9 (PHQ-9)

This study employed the PHQ-9 to assess the depressive symptoms in the participants. The scale is derived from the depression module of the Patient Health Questionnaire (PHQ) developed by Spitzer et al. in 1999*(52)* and is now widely used in clinical depression screening. The scale consists of 9 items that assess the participant's depressive mood over the past 2 weeks, using a 4-point scoring system ranging from 0 "not at all" to 3 "nearly every day". Higher scores indicate a greater severity of depression, where 0-4 indicates no depression, 5-9 indicates mild depression, 10-14 indicates moderate depression, and 15 or higher indicates severe depression. In this study, the scale's alpha coefficient was 0.90; the structural validity measures were: X^2/df=15.99, RMSEA=0.12, SRMR=0.05, CFI=0.92, TLI=0.89, with standardized factor loadings ranging from 0.53 to 0.84.

2.2.3 Psychological Capital Questionnaire

This study used the Positive Psychological Capital Questionnaire developed by Zhang et al *(53)* to assess the positive psychological states of employees in enterprise and institution during their growth and development. The scale comprises four dimensions: optimism, hope, self-efficacy, and resilience, with a total of 26 items, including reverse scoring for items 8, 10, 12, 14, and 25. The questionnaire employs a seven-point Likert scale, ranging from 1 "completely disagree" to 7 "completely agree". Higher scores indicate a greater positive orientation of psychological capital. After testing, the Cronbach's alpha coefficient for the questionnaire in this study was 0.95, and the structural validity measures were X^2/df=11.46, RMSEA=0.10,

Table 1 Basic Information of Survey Participants

Distribution Characteristics	Number	Percentage	Distribution Characteristics	Number	Percentage
Educational Level			Position Category		
Middle school or below	111	10.82%	Enterprise Staff	543	52.92%
High or vocational school	145	14.13%	Enterprise Management	205	19.98%
College or Bachelor	691	67.35%	Government Agency	278	27.10%
Postgraduate	79	7.70%			

SRMR=0.08, CFI=0.84, TLI=0.82, with standardized factor loadings ranging from 0.32 to 0.91. Items 2, 8, 10, 14, and 25 had standardized loadings below 0.5. Considering the homogeneity of these items' descriptions with others, their deletion resulted in the following structural validity measures: X^2/df=9.06, RMSEA=0.09, SRMR=0.05, CFI=0.91, TLI=0.90, indicating good reliability and validity. Therefore, these five items were excluded from the subsequent statistical analysis of psychological capital.

2.2.4 Job Burnout Questionnaire

The Job Burnout Questionnaire developed by Li *(54)* has been widely used in various professional fields, including teaching, law enforcement, business management, and corporate settings, to assess the behavioral and emotional exhaustion experienced by employees under prolonged stress. The questionnaire comprises three dimensions: exhaustion, depersonalization, and reduced personal accomplishment, consisting of 15 items scored on a 7-point scale, ranging from 1 "completely disagree" to 7 "completely agree," with reverse scoring applied to items 3, 6, 9, 12, and 15. A higher total score indicates a greater degree of job burnout. In this study, the Cronbach's alpha coefficient for the questionnaire was 0.86, and the structural validity measures were X^2/df=6.38, RMSEA=0.07, SRMR=0.06, CFI=0.92, TLI=0.90, with standardized factor loadings ranging from 0.38 to 0.88. After removing all items with standardized loadings below 0.5—namely, items 3 and 6—the structural validity measures of the questionnaire were X^2/df=6.03, RMSEA=0.07, SRMR=0.05, CFI=0.94, TLI=0.93. The revised questionnaire was used to assess the job burnout levels among employees.

2.3 Data Analysis

Firstly, analyze the current status of depression among employees in enterprises and institutions, and use SPSS27.0 to examine the differences in depression scores across various employee groups, such as gender, educational level, and job position category, with $p<0.05$ considered significant.

Secondly, to examine the significant impact of work stress on employee depression in enterprises and institutions, this study ranked the work stress scores of participants and selected the top 27% and bottom 27% as the high and low work stress group, respectively. Conduct independent sample t-tests on these two groups, with $p<0.05$ considered significant.

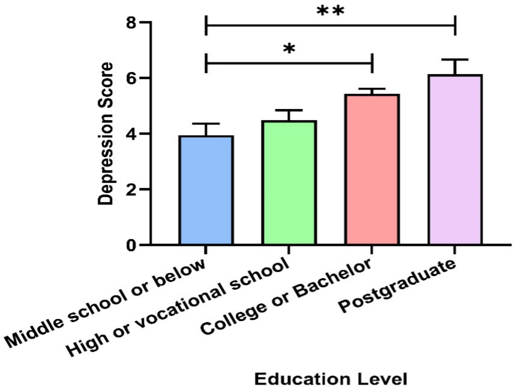
Thirdly, a structural equation analysis of work stress, psychological capital, job burnout, and depression was performed using Mplus (v8.3). The Bootstrap method was used to assess the mediating effects (n=5000, 95%CI). Specifically: (1) test the measurement model; (2) compute descriptive statistics and perform correlation analysis of these four variables; (3) establish and evaluate the structural equation of these variables, incorporating control variables (e.g., age, gender, position category, educational level) into the model. Specifically, work stress is treated as the independent variable, depression as the dependent variable, psychological capital and job burnout as mediators, and control variables as covariates for chain mediation testing. When the confidence interval does not include 0, it indicates that the mediating effect is significant*(55)*.

3 Results

3.1 Group Differences in Employee Depression

In this study, 52.2% of employees in enterprises and institutions showed no depression, 34.0% had mild depression, 9.0% had moderate depression, and 4.6% had severe depression. A score of 10 on the PHQ-9 is the cut-off point*(56)*, and the prevalence of moderate to severe depression among employees is 13.6%.

An independent samples t-test was conducted to compare the gender differences in depression scores among employees. The results indicated no significant difference in depression scores between males and females. A one-way ANOVA was performed to analyze the depression scores of employees with different educational backgrounds. The results showed that educational level significantly affected the depression scores of employees ($F_{(3,1022)}$=5.37, p=0.001, partial n^2=0.02), with a general trend indicating the higher educational levels were associated with higher depression levels. Postgraduate and undergraduate (or college) depression scores were significantly higher than those of junior high school students (or below), as shown in Figure 2.



Education Levels (Note: * represent $p<0.05$, ** represent $p<0.01$, *** represent $p<0.001$, same below)

A variance analysis was conducted on the depression scores of employees in different positions, and the results revealed significant differences in depression scores among employees in these positions (Welch $F_{(2,\ 516.22)}=11.67$, $p<0.001$, partial $n^2=0.02$). Specifically, the depression levels of government agency are significantly higher than those of enterprise staff, and the depression levels of enterprise staff are significantly higher than those of enterprise management ($p<0.05$), as shown in Figure 3.

3.2 The Impact of Work Stress on Depression Among Employees

An independent samples t-test was performed on the high and low work stress groups, revealing that the depression scores of the high work stress group (7.83±5.42) were significantly higher than those of the low work stress group (2.52±3.03) $t_{(432.79)}=14.23$, $p<0.001$, Cohen d=1.21. This suggests that employees' work stress influences their depressive symptoms.

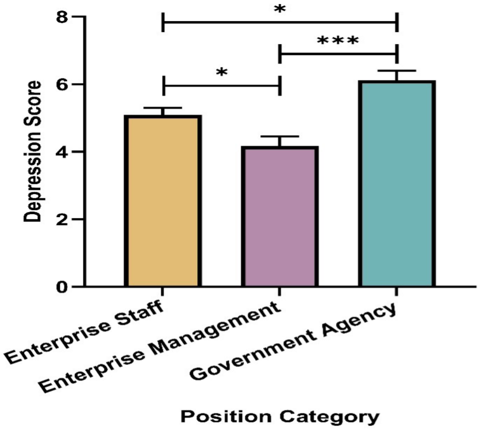


Figure 3. Employees Depression in Different Positions

3.3 The Chain Mediation Effect of Psychological Capital and Job Burnout

3.3.1 Test the Measurement Model

To evaluate the validity of the measurement model proposed in this study, we performed a series of confirmatory factor analyses on all items, specifically work stress (3 items), psychological capital (21 items), job burnout (13 items), and depression (9 items). As shown in Table 2, the fit indices for our hypothesized four-factor model are: X^2/df=8.41, RMSEA=0.09, SRMR=0.06, CFI=0.92, and TLI=0.90. This model demonstrated a better fit compared to the best competing model (a three-factor model that combines work stress and job burnout: X^2/df=13.42, RMSEA=0.11, SRMR=0.10, CFI=0.85, TLI=0.83). Additionally, among all models, the single-factor model exhibited the poorest fit (see Table 2). The Harman single-factor test further indicated that there were 8 factors with eigenvalue greater than 1,with the first factor explaining 34.34% of the variance, which is below the critical threshold of 40% *(57)*. these findings suggest that common method bias is not present in the multivariate data of this study.

N = 1026. CFI, Comparative Fit Index; TLI, Tucker-Lewis Index; RMSEA, Root Mean Square Error of Approximation; SRMR, Standardized Root Mean Square Residual.

3.3.2 Description of Statistics and Correlation Analysis

The means, standard deviations, and correlations of all variables are presented in Table 3. Work stress, depression, and job burnout exhibited significant positively correlations (r=0.49~0.65, p<0.001), whereas psychological capital showed significant negative correlations with work stress, depression, and job burnout (r=-0.62~-0.29, p<0.001). Age was significantly positively associated with work stress (r=0.13, p<0.001) and psychological capital (r=0.14, p<0.001), while it was negatively associated with depression (r=-0.09, p<0.01) and job burnout (r=-0.08, p<0.05).

3.3.3 Chain Mediation Analysis

First, the effects of age, gender, educational level and job position category on psychological capital, job burnout and depression were examined. According to the above analysis, age is associated with depression, psychological capital and job burnout, while job position category and educational level influence employees' depression scores.

Table 2 Measurement Model Test

Measurement Models	X^2	p	df	ΔX^2	CFI	TLI	RM-SEA	SRMR
Assumed four-factor model	1227.34	<0.001	146	——	0.92	0.90	0.09	0.06
Competing Models								
Three-Factor Model Combining Work Stress and Depression	2564.96	<0.001	149	1337.62	0.81	0.78	0.13	0.08
Three-Factor Model Combining Work Stress and Job Burnout	1999.69	<0.001	149	772.35	0.85	0.83	0.11	0.10
Three-Factor Model Combining Job Burnout and Depression	1781.03	<0.001	149	553.69	0.87	0.85	0.10	0.08
wo-Factor Model Combining Work Stress, Job Burnout, and Depression	2880.01	<0.001	151	1654.67	0.79	0.76	0.13	0.09
Single-Factor Model of All Latent Variable Combinations	5042.34	<0.001	152	3815.00	0.61	0.57	0.18	0.11

Table 3 Description Statistics and Correlation Analysis Results for All Variables

Variable	M	SD	1	2	3	4
1.Work Stress	8.11	2.70	1			
2.Depression	5.19	4.74	0.49^{***}	1		
3.Psychological Capital	105.73	18.75	-0.29^{***}	-0.46^{***}	1	
4.Job Burnout	35.39	12.01	0.56^{***}	0.65^{***}	-0.62^{***}	1
5.Age	37.29	8.43	0.13^{***}	-0.09^{**}	0.14^{***}	-0.08^{*}

Note: *** represents $p < 0.001$, ** represents $p < 0.01$, * represents $p < 0.05$.

Further analysis of the effects of gender, job position category and educational level on psychological capital and job burnout revealed: (1) there is a significant gender difference in psychological capital (male: 108.33 ± 18.34, female: 104.33 ± 18.83, $t_{(1024)}$ =3.28, p=0.001, Cohen d=0.22); (2) all other tests yielded non-significant results. The above control variables with significant differences were incorporated into the structural equation model, with work stress as the independent variable, depression as the dependent variable, psychological capital and job burnout as mediating variables, age, job position category and educational level as control variables for depression, age and gender as control variables for psychological capital, age as a control variable for job burnout. The results show that the model fit indices were: X^2/df=6.50, RMSEA=0.07, SRMR=0.06, CFI=0.90, TLI=0.89, as illustrated in Figure 4 (for simplify, control variables were omitted). Specifically, (1) the direct effect of work stress on depression was not significant; (2) psychological capital did not mediate the relationship between work stress and depression; (3) job burnout mediated the effect of work stress on depression (Effect=0.31, 95%CI= [0.24,0.39]); (4) psychological capital and job burnout exhibited a serial mediating effect on the relationship between work stress and depression (Effect=0.08, 95%CI= [0.05,0.13]).

4 Discussion

4.1 Current Status of Employee Depression

According to the survey, 52.2% of employees exhibit no depression, 34.0% experience mild depression, 9.0% have moderate depression, and 4.6% suffer from severe depression. Based on the critical value classification standard proposed by Wang et al.*(56)*, a PHQ-9 score of 10 was used as the threshold, with 13.6% of employees scoring above this cutoff, indicating a need for special attention.

The job position category and educational level both have significant effects on employees' depression scores. Specifically, employees working in government agencies have significantly higher depression scores than enterprise staffs, who, in turn, have significantly higher depression scores than enterprise managers. The findings of this study are largely consistent with the results of *the Report On National Mental Health Development In China*(2021-2022)*(49)*. Although the report didn't assess the depression levels of government agencies, it found that managers had the lowest depression scores, whereas service industry workers, self-employed individuals, and company staff exhibited moderate depression scores. However, in contrast to the findings of Madigan and Daly*(58)*, this study did not observe a decrease in depression levels with increasing educational level. Instead, the trend was reversed: Higher education levels were associated with higher depression score. Employees with graduate or undergraduate (or college) degrees had significantly higher depression scores than those with junior high school (or lower) de-

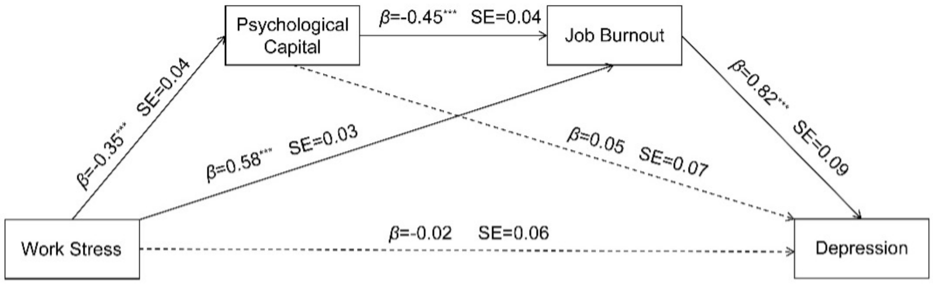


Figure 4 The Chain Mediation Effect of Psychological Capital and Job Burnout in the Relationship Between Work Stress and Depression

grees. The discrepancy in results may be attributed to the uneven distribution of data across different educational categories. For example, individuals with undergraduate (or college) degrees accounted for 67.3% of the sample, whereas those with graduate degrees comprised only 7.7%, which may have influenced the findings of this study.

4.2 Work Stress and Depression

This study ranked employees' work stress scores and categorized the top 27% and bottom 27% of participants as the high and low work stress groups, respectively. An analysis of the differences in depression scores between the two groups revealed that employees in the high work stress group had significantly higher depression scores than those in the low work stress group. This finding aligns with previous research, indicating that work stress is a significant determinant of employee depression*(56,59)*, supporting both the Effort-Reward Imbalance Model and the Demand-Control Model. However, when the work stress score was treated as a continuous variable in the mediation model, the direct effect of work stress on depression was not significant. The statistical results derived from group categorization may amplify the impact of extreme scores while overlooking intermediate scores, thereby increasing the likelihood of obtaining significant results due to exaggerated group differences. In contrast, modeling work stress scores as a continuous variable provides a more precise estimation of the relationship between work stress and depression. Combined with the subsequent analysis, these findings suggests that the effect of work stress on employee depression is mediated, indicating that the impact of work stress on depression is primarily exerted through indirect pathways.

4.3 The Intrinsic Mechanism of Work Stress Affecting Depression

Job burnout serves as a significant mediator in the relationship between work stress and depression, supporting Hypothesis 1. This is aligns with previous research, which identifies job burnout as a crucial pathway through which work stress impacts mental health*(20)*. Prolonged work stress may result in job burnout, manifesting as emotional exhaustion, depersonalization and reduced personal accomplishment, along with symptoms such as fatigue, diminished job satisfaction, self-doubt, and physical discomfort, ultimately heightening the risk of depression. The findings further support the stress-stressor-health outcome model, suggesting that work stress does not directly impact employee depression but instead affects depression levels by eliciting a psychological stress response (i.e., job burnout).

Moreover, work stress can influence employee depression by depleting psychological capital which subsequently leads to job burnout. In other words, psychological capital and job burnout jointly mediate the relationship between work stress and employee depression in a sequential manner. Psychological capital significantly mediates the relationship between work stress and job burnout; however, its mediating role between work stress and depression is not significant, supporting Hypothesis 2. These findings are consistent with Avey et al. *(42)*, indicating that negative emotions contribute to depression only after accumulating to a critical level and leading to psychological exhaustion (quantitative to qualitative change). As outlined in the Conservation of Resources Theory, high work stress depletes psychological capital, and the continuous depletion of psychological capital serves as a key driver of job burnout*(60)causing mass turnover, especially of primary medical staff. Little attention has been paid to the different dimensions of job burnout (emotional exhaustion, personality disintegration, and reduced sense of achievement.* Once resources are exhausted, individuals suffer from emotional exhaustion, depersonalization, and reduced sense of personal accomplishment, along with impaired coping ability, a sense of loss of control, and helplessness, ultimately heightening the risk of depression. Therefore, to mitigate or prevent depression induced by work stress, enhancing employees' psychological capital or alleviating job burnout are both effective intervention strategies.

4.4 Ethical review

As social entities with both economic and ethical functions, companies bear social responsibilities such as production, livelihood, and education. The divergence between instrumental rationality and value rationality has led to differences in the ethical practices of companies. For example, companies that operate primarily on instrumental rationality, without ethical guidelines, often increase work demands in pursuit of profit maximization. On the other hand, companies that emphasize value rationality and ethical principles tend to adopt a “people-oriented” ethical approach. It is evident that different companies exhibit varying value orientations in their ethical practices. Finding a balance between profit-seeking and ethical values is crucial for the harmonious development of both the company and its employees. This study reveals that personal psychological factors, such as psychological capital and work burnout, can mitigate the negative impact of work stress on employee depression. This may represent a potential balance point between profit and ethics for companies. Based on this finding, companies should proactively offer psychological health support to employees and implement more detailed intervention measures. During the implementation process, it is also essential to ensure the ethicality of psychological interventions. Specifically:

First, enterprises should prioritize employees with moderate to severe depression and implement targeted mental health screening and intervention programs. Psychological counseling, health lectures or supportive groups*(61)* can provide professional assistance to individuals at high-risk of depression and help reduce their depression levels. However, this does not mean that employees with less severe depression should be overlooked. When providing mental health services, companies should ensure that all employees have equal access to benefits. They should avoid labeling mental health services as being solely for specific groups, and instead offer preventive and supportive services to all employees.

Second, managing job burnout should be considered a key strategy for alleviating employee depression. Enterprises should implement effective measures to mitigate employee job burnout, such as optimizing management systems (e.g., Employee Assistance Programs, *62*), establishing appropriate work-rest mechanisms, enhancing employee autonomy, and fostering a sense of value and achievement in their workplace. And, enhancing the employees’ psychological capital can serve as a protective mechanism against the impact of work stress on job burnout and depression. Enterprises can adopt psychological capital intervention strategies, such as hope training, optimism cultivation, self-confidence building, resilience development, to help employees strengthen their psychological resources. In work environments that cannot be easily modified, strengthening employees’ resilience can fundamentally enhance their ability to cope with stress and reduce the risk of depression. It is important to note that these interventions must also adhere to ethical principles. For instance, mental health interventions should not be overly coercive. When intervening in employees’ mental health, companies must respect employees’ autonomy and right to choose. Employees must give informed consent and voluntarily participate, ensuring that no form of coercion is involved.

Finally, the mental health services provided by companies should be sustainable and yield long-term benefits. Companies should avoid focusing solely on short-term improvements while overlooking the long-term health management needs. To ensure the continued effectiveness of these interventions, companies should implement ongoing tracking and evaluation. Moreover, any personal or mental health data involved in the intervention process should be anonymized and kept confidential to prevent data breaches or misuse, thereby safeguarding employees from potential negative consequences.

5 Conclusion

This study found that: (1) 13.6% of employees suffer from moderate or severe depression, and highlighting the need for enterprises to pay special attention to this population; (2) Job burnout mediates the relationship between work stress and employee depression, thereby amplifying the impact of work stress on worker depression; (3) Psychological capital and job burnout jointly mediate the effect of work stress on employee depression in a sequential manner. Work stress affects employee depression by depleting psychological capital which in turn drives job burnout. Enhancing psychological capital can mitigate job burnout among employees and lower the risk of depression.

Data Sharing Statement

The data that support the findings of this study are available on request from the first author (E-mail: zqhououou@126.com). The data are not publicly available due to privacy or ethical restrictions.

Ethics Approval Statement

This study complies with the ethical principles outlined in the Declaration of Helsinki. This study was approved by the Ethics Research Committee of the Tianjin Normal University (No.2023112304). The cover page of the questionnaire explained the study's purpose and assured participants of their anonymity, confidentiality, and right to refuse participation.

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Author Contributions

QZ: Conceptualization, Formal analysis, Methodology, Writing – original draft, Writing – review & editing. JL: Data curation, Investigation, Visualization, Writing – original draft. KT: Conceptualization, Methodology, Validation, Methodology, Writing – original draft, Writing – review & editing, Funding acquisition.

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AUTONOMÍA Y BÚSQUEDA DE CUIDADOS EN SALUD MENTAL ADOLESCENTE

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Resumen: Una de las principales estrategias para la prevención en salud mental es el acceso oportuno a ayuda profesional. No obstante, distintas barreras dificultan que los adolescentes y jóvenes reciban de manera temprana esta atención profesional. El objetivo del presente artículo es reflexionar sobre el rol de la autonomía en la búsqueda de ayuda en salud mental en población adolescente. Se plantea el constructo de "autonomía" desde una perspectiva de psicología del desarrollo y desde la ética. Luego, se presenta y describe evidencia de investigaciones que relacionan a la autonomía con temas de salud mental, con algunos constructos relacionados con el ajuste psicológico y con la conducta de búsqueda de ayuda para problemas de salud mental. A partir de lo evidenciado, se discuten implicancias y lineamientos para la prevención en salud mental.

Palabras clave: autonomía, salud mental, adolescentes, búsqueda de ayuda, barreras, acceso a tratamiento

Autonomy and care -seeking in adolescent mental health

Abstract: One of the main strategies for mental health prevention is timely access to professional help. However, different barriers make it difficult for adolescents and young people to receive early access to professional care. The aim of this article is to reflect on the role of autonomy in seeking mental health help in the adolescent population. The construct of autonomy is approached from a developmental psychology and bioethical perspective. Then, research evidence is presented and described that relates autonomy with mental health issues, with some constructs related to psychological adjustment, and with help-seeking behavior for mental health problems. Based on this evidence, implications and guidelines for mental health prevention are discussed.

Key words: autonomy, mental health, adolescents, help-seeking, barriers, treatment Access

Autonomia e procura de cuidados em saúde mental por adolescentes

Resumo: Uma das principais estratégias para a prevenção em saúde mental é o acesso oportuno a ajuda profissional. Não obstante, distintas barreiras dificultam que adolescentes e jovens recebam de forma precoce esta atenção profissional. O objetivo do presente artigo é refletir sobre o papel da autonomia na procura de ajuda em saúde mental na população adolescente. Se propõe o construto de "autonomia" a partir de uma perspectiva da psicologia do desenvolvimento e da ética. Em seguida, são apresentadas e descritas evidencias de pesquisas que relacionam a autonomia com temas de saúde mental, com alguns construtos relacionados com o ajustamento psicológico e com o comportamento de procura de ajuda para problemas de saúde mental. Com base nessas evidencias, são discutidas implicações e diretrizes para a prevenção em saúde mental.

Palavras-chave: autonomia, saúde mental, adolescentes, procura de ajuda, barreiras, acesso a tratamento

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Introducción

La adolescencia representa un periodo crítico para el desarrollo de la salud mental, estimándose que alrededor del 48% de las condiciones mentales de manifiestan antes de los 18 años*(1)*. Entre estas, los trastornos de ansiedad y depresión son los de mayor prevalencia en población adolescente, con tasas de 3,6% y 5,5%, respectivamente*(2-5)* Estas condiciones tienen múltiples repercusiones en el bienestar de los adolescentes, afectando su desarrollo, calidad de vida y aumentando el riesgo de problemas de salud en la adultez*(6-8)depression and quality of life (QoL*.

Las recomendaciones internacionales proponen un enfoque integral de la salud que combine el bienestar mental, social y físico a través del fortalecimiento de sistemas de prevención, intervención efectiva y la generación de sistemas de información robustos basados en evidencia*(9)*. En este sentido, factores contextuales como los aspectos socioeconómicos, familiares y ambientales han tomado relevancia en estudio e intervención de la salud mental adolescente, tanto como factores de riesgo para el desarrollo de patologías como en la influencia que tienen en el acceso a los recursos disponibles*(10,11)*.

A pesar de esto, aún muchos adolescentes no acceden a servicios de salud mental o tratamientos psicológicos en diferentes zonas del mundo*(12-15)*. Los adolescentes tienden a no buscar ayuda para temas de salud mental y, cuando lo hacen, recurren más bien a fuentes informales, como familiares y amigos*(16-19)*. Asimismo, estudios han identificado que, frente a la presencia de algún tipo de sintomatología en salud mental, los adolescentes y jóvenes tienden a buscar menos ayuda*(20,21)*. Por ejemplo, en el estudio de Hall et al (2019) los adolescentes que reportaron mayor estrés psicológico buscaron menor ayuda que aquellos que no lo presentaban (7,0% en comparación al 36,5%), a pesar de considerar que sí necesitaban ayuda*(20)*. Estudios similares enfocados en la depresión han evidenciado que los adolescentes que presentan mayores síntomas de depresión son los que muestran mayor resistencia a buscar ayuda, encontrándose que la presencia de síntomas depresivos clínicos está asociada con una mayor intención de no búsqueda de ayuda, en comparación con aquellos que no presentan síntomas o presentan síntomas subclínicos (Baldofski et al., 2024). En la misma línea , el estudio de McGillivray con adolescentes y jóvenes de 16 a 25 años que habían experimentado ideación suicida constató que, teniendo la posibilidad de buscar ayuda profesional, solo un 39% de los jóvenes había revelado esta ideación y pedido ayuda a algún prestador de salud mental*(21)*.

En Chile la situación refleja desafíos similares y crecientes. El Instituto Nacional de la Juventud (2021) reporta que el 46% de los adolescentes presentan síntomas de ansiedad o depresión y el 18% tiene un consumo problemático de sustancias. El Departamento de estadísticas e información de salud (2024) también indica que desde 2022 las poblaciones de 10 a 14 y de 15 a 19 años son el quinto y sexto grupo etario más frecuente en recibir atenciones en el Programa de Salud Mental, con un total de 921.754 atenciones en 2023. Un estudio realizado en Chile sobre uso de servicios de salud mental con adolescentes de 13 a 18 años constató una importante brecha en el acceso a tratamiento, ya que un 80% de los jóvenes que cumplen con criterio para problema de salud mental no estaba en tratamiento actual*(24)*.

Estudios locales confirman que los adolescentes en Chile suelen recurrir principalmente a padres, amigos y parejas antes que a fuentes formales de ayuda*(18,19)*, replicando las tendencias internacionales y reflejando la importancia de fortalecer los sistemas de salud y apoyo en torno a esta población.

Distintas investigaciones han identificado barreras para el acceso a la atención profesional en este grupo*(25,26)*. Entre las que han sido identificadas para esta no búsqueda de ayuda se identifican la percepción de autosuficiencia, el temor a la pérdida de confidencialidad, el estigma, la falta de acceso directo y sencillo a servicios especializados y la falta de alfabetización en salud mental*(17,18,25,27-29)*.

Una de las barreras identificada en algunos estudios, y que ha sido menos estudiada*(25,30,31)* en relación con la búsqueda de ayuda en salud mental, es la necesidad de autonomía de los adolescentes y jóvenes. En el presente artículo se presenta evidencia de la literatura científica que ha estudiado la variable de autonomía y el acceso a cuidados o búsqueda de ayuda para problemas de salud mental, para luego aportar elementos de análisis desde una perspectiva ética y, finalmente, proponer algunas consideraciones para el abordaje de los adolescentes a partir de lo revisado.

Concepto de "autonomía" desde psicología

Desde una perspectiva evolutiva, la adolescencia plantea distintas tareas, estando entre las principales la búsqueda de un sentido de identidad, el desarrollo de la competencia emocional y social, y el desarrollo de la autonomía*(32)*.

Beyers et al.*(33)* han planteado que el concepto de "autonomía" en adolescentes puede concebirse principalmente de dos maneras: la primera estaría vinculada a la autosuficiencia e independencia, y la segunda a la volición.

La autonomía como independencia significa comportarse, tomar decisiones o pensar sin depender de otros. Lo contrario a esto es la dependencia, y de los padres particularmente en la adolescencia. Para alcanzar la independencia el adolescente se va separando progresivamente de su familia de origen, lo que puede conllevar un grado de conflicto con sus padres, y va estableciendo lazos emocionales cada vez más profundos con personas de su misma edad, cambiando por tanto su centro emocional desde la familia a sus pares*(32)*.

La segundo tipo de autonomía, según Beyers*(33)*, es la autonomía como volición, es decir, relacionada a la libertad psicológica. Esta aproximación está vinculada a la teoría de la autodeterminación, en la que la autonomía, la competencia y la relación constituyen necesidades psicológicas básicas, y la satisfacción de estas necesidades conduce a un mayor bienestar tanto en adolescentes como en adultos. Se puede definir la autonomía como una necesidad psicológica fundamental y un ingrediente esencial para el desarrollo saludable y el bienestar*(34)*. La autonomía se refiere a un sentido de voluntad y control sobre los sentimientos, pensamientos y acciones. Las personas se sienten autónomas cuando experimentan el autogobierno dentro de sus vidas y tienen la capacidad de tomar decisiones que son congruentes con sus intereses, metas y valores personales. Por el contrario, la autonomía se ve disminuida cuando fuerzas externas controlan o coaccionan pensamientos y comportamientos, lo que a menudo genera estrés y conflictos internos con consecuencias perjudiciales para el bienestar*(34,35)*. La autonomía es considerada un recurso relevante para el ámbito de la salud individual, ya que puede incentivar la motivación autónoma y contribuir a una mejor salud mental*(36)*.

El rol de los padres en el desarrollo de la autonomía ha quedado evidenciado en investigaciones que han identificado cómo las prácticas de apoyo a la autonomía son fundamentales para un sano y adecuado desarrollo de la inteligencia emocional en adolescentes*(37)*.

Cabe destacar que la adquisición de la autonomía incluirá para el adolescente el aprendizaje de cómo tomar decisiones en los distintos ámbitos, por ejemplo, educación, relaciones interpersonales, trabajo y conductas de salud*(38)*, como es la búsqueda de tratamiento y ayuda en salud y salud mental.

A**utonomía y salud**

La autonomía también se ha relacionado con la salud y, concretamente, con distintos constructos que dan cuenta de esto, entre otros el bienestar psicológico*(39)* y el de calidad de vida*(40)*. Desde el bienestar psicológico*(39)* se ha considerado la autonomía incluso como una parte del constructo de bienestar.

Reconociendo la relevancia del desarrollo de la autonomía en salud en población adolescente, la OMS, en 2021, publicó una guía que describe un proceso de cuatro pasos para evaluar y apoyar la capacidad de autonomía en la toma de decisiones en el trabajo de los profesionales de la salud con este grupo etario*(41)*: Exploración conjunta de la situación y opciones; Síntesis común de la situación; Punto de decisión (decidir si el adolescente tiene la capacidad de tomar decisión autónoma en una situación dada en un momento dado); Seguimiento (esquema de directrices para el seguimiento).

En Chile, el Programa Nacional de Salud Integral de adolescentes y jóvenes*(42)* plantea entre sus consideraciones éticas sobre la atención en salud a la autonomía, indicando que se asume que él o la adolescente posee la libertad necesaria para actuar en forma independiente de influencias externas y tiene la capacidad para actuar intencionadamente. Asimismo, plantea que este principio aplicado a la atención clínica se basa en la comprensión de los adolescentes de la información entregada por los equipos de salud, lo que implica, para quien brinda la atención, entregar información que le permita al o la adolescente comprender la situación que enfrenta, los valores que están en juego, las posibles acciones y consecuencias, y que pueda comunicar libremente sus preferencias y así tomar la mejor decisión en salud.

Estudios sobre autonomía y salud mental en adolescentes

La autonomía es una característica propia del adolescente y es necesario desarrollar este sentido; no obstante, existe alguna evidencia de que esta variable, que es esperable, vaya desarrollándose en este etapa de la vida; a su vez, también puede llegar a ser un obstáculo para la búsqueda de ayuda cuando se está frente a un problema de salud mental*(30)*.

En una revisión cualitativa de síntesis reciente, sobre barreras y facilitadores para buscar tratamiento en salud mental*(43)*, se concluyó que los adolescentes deben tener autonomía para participar en el tratamiento de salud mental, y se sugiere que, para mejorar la participación en los tratamientos, se realicen intervenciones que aborden su capacidad de ser autónomos.

Otro estudio de Wang y colaboradores*(44)*, que buscó mediante metodología mixta estudiar las barreras para la búsqueda de ayuda en salud mental en población de adolescentes escolarizados de entre 11 y 19 años de minorías culturales, identificó 4 temas, siendo la "independencia" una de estas. En este estudio, los participantes plantearon que algunos adolescentes desean manejar por sí mismos sus problemas, sin depender de sus familias o amigos, y que "querían sentirse más adultos". También referían que este deseo de independencia se relaciona con cierto "orgullo" o "terquedad", considerando que todo adolescente puede pasar por problemas similares y que, por tanto, deberían resolverlos solos. Finalmente los adolescentes también indicaron que este deseo de independencia y resistencia a buscar ayuda profesional se relacionaba también con el evitar ser coaccionados por sus padres para recibir tratamiento, y que esto sería una forma de control y restricción de su libertad*(44)*.

Asimismo, en intervenciones preventivas del suicidio, denominadas "plan de seguridad", se han propuesto siete factores a considerar en los pasos de esta intervención, siendo la promoción de autonomía uno de estos*(45)*.

Vinculado a la autonomía se tiene un segundo constructo que también ha sido objeto de investigación en la prevención en salud mental adolescente: la autosuficiencia, que involucra la percepción de tener que resolver los problemas por sí mismo(a).

En un estudio que aborda esta variable, realizado con 2.150 estudiantes en el contexto de un programa de detección para la prevención del suicidio*(46)*, se constató que presentar un nivel de autosuficiencia extrema estaba asociado con una menor búsqueda de ayuda, síntomas depresivos significativos e ideación suicida grave en la evaluación inicial. Además, en los jóvenes identificados en condición de riesgo en la evaluación inicial, la autosuficiencia extrema predijo el nivel de ideación suicida y síntomas depresivos dos años después, incluso después de controlar los síntomas iniciales. Considerando estos hallazgos, los autores proponen que las actitudes que refuerzan el comportamiento de autosuficiencia extrema pueden ser un objetivo importante para los programas de prevención del suicidio juvenil. Asimismo, reducir la autosuficiencia extrema en jóvenes con tendencias suicidas podría aumentar su probabilidad de buscar ayuda adecuada y la reducción de los síntomas asociados.

Al hablar de autonomía es también importante considerar el rol de la familia en la búsqueda de ayuda. Al respecto, existe evidencia del papel de la transmisión intergeneracional de la conducta de búsqueda de ayuda para problemas de salud mental en adolescentes, y se ha identificado como varía la autonomía en función de la capacidad de los padres de reconocer los problemas de salud mental. En los casos en que los padres reconocían que sus hijo tenían un problema, la autonomía del adolescentes no influía mayormente en la conducta de búsqueda de ayuda; no obstante, cuando los padres no reconocían los síntomas de su hijo como un problema de salud mental el factor "autonomía" cobraba un rol relevante para que el adolescente pudiera llegar a recibir ayuda profesional*(47).*

Frente al problema de que los padres no siempre buscan ayuda para su hijos que presentan necesidades en salud mental, se concluye que es importante trabajar también con los padres para que él o la adolescente pueda llegar realmente a un profesional de salud mental. Es deseable entonces desarrollar también intervenciones que promuevan la búsqueda de ayuda en los padres*(48)*.

Autonomía desde la perspectiva ética

La identificación de la *psiché* (alma) con aquel principio interno que gobierna al ser humano lo encontramos ya en el diálogo "Alcibíades" de Platón. De ahí viene la concepción que aquello que fundamenta la unidad de la individualidad humana es un elemento que gobierna y orienta todas las funciones del sujeto hacia lo que le es esencial, dándole, de ese modo, su consistencia e identidad individual. En el campo del saber bioético, la conjunción de las nociones de autogobierno y libertad constituyen las condiciones esenciales de la autonomía personal. En otras palabras, tanto la propia capacidad para ejercer una acción como la independencia de influencias que la coarten cuentan entre los elementos más elevados e ideales que ostenta la persona humana*(49)*. Si bien el consenso bioético llama a reconocer, respetar y cuidar la capacidad de autodeterminación en las decisiones como uno de los reductos inviolables de la identidad personal, existe diversos debates en torno a las fuerzas que socavan o dañan severamente la capacidad de un sujeto de tomar decisiones autónomas y a los criterios para considerar una autonomía como suficiente.

Como lúcidamente*(50)* puntualizan, no es claro que, aun cuando de hecho podamos decidir sobre nuestras acciones, el poder para decidir no esté movilizado por fuerzas que nos controlan de manera sutil. Nadie se autogobierna de manera pura sin estar sujeto a algún tipo de influencia cuyo poder no deriva de su propia autoridad. De ahí que la pregunta por la autonomía en un plano filosófico se ha concentrado en la metafísica de la agencia, que se interroga acerca de ¿cuáles son los criterios para considerar una autonomía suficiente en la toma de decisiones? ¿Sobre qué base la autonomía de un sujeto puede ser subrogada? ¿Cómo distinguir las fuerzas que socavan la autonomía de aquellas que motivan efectivamente las propias decisiones y su proceso de autogobierno?

Algunos autores centran su atención en los rasgos del carácter del agente que dan una unidad a la personalidad o permitan considerarla "integrada". De ahí sostienen que la autonomía se logra si las decisiones son coherentes a largo plazo con los propios planes, intereses o valores*(51)*. Otra perspectiva entiende que la autonomía es la capacidad de sostener juicios evaluativos que respondan a razones para actuar de una determinada manera. En otras palabras, la autonomía se fundaría en la capacidad de conformar el actuar en el juicio propio y en la evaluación que se haga de ellos. La manifestación de la propia autoridad o autogobierno se daría en los razonamientos que respaldan las actuaciones como propias. Esta visión está vinculada con la noción de responsabilidad moral. Sin embargo, estas ideas no salvan la posibilidad de influencia internas a la capacidad misma de razonar, como el adoctrinamiento u otras formas de sujeción de conciencia, propias de las sectas. En esos casos la persona mantiene su capacidad de razonar, solo que han interiorizado ideas que debilitan o anulan su propia autodeterminación. Sus razonamientos no son los propios. Lo mismo puede ocurrir en un sentido inverso: una persona con una fuerte adicción puede estar tan dominado por su condición que por mucho que desarrolle razonamientos y conclusiones en torno a sus decisiones difícilmente estas puedan ser atribuidas a ella. Por otro lado, es complejo determinar cuáles son los principios de racionalidad que debieran guiar los razonamientos y discriminar la articulación compleja que se da entre las consideraciones teóricas (creencias) de las prácticas a la hora de establecer un criterio de autonomía centrado en la capacidad de sostener un proceso de razonamiento. En este punto*(50)*, reconocen la dificultad de poder identificar las condiciones mínimas para la autonomía, lo que constituye un foco para nuestro trabajo en la medida que el deterioro de la salud mental puede socavar las formas en que un agente cumple los diversos desempeños que implican las decisiones y acciones propias. De hecho, en las explicaciones que apuntan al razonamiento es difícil determinar en qué medida un buen razonamiento da o socava la autonomía. En este punto la capacidad de autorreflexión, es decir de poder tomar distancia incluso de los propios razonamientos y actitudes permite entender un concepto de "autonomía" que permita la flexibilidad necesaria para poder cambiar convicciones y creencias, si hay buenas razones para aquello. Esto no significa que la autonomía sea un espacio para el cambio de preferencias y motivos para actuar*(52)*, es decir, que la persona no tenga o no pueda alcanzar en cada momento una estabilidad de su carácter que le dé una coherencia o integridad de su persona. Justamente, un menoscabo de la salud mental justamente puede alterar de diversas formas todas las condiciones que se aluden en el debate que, por cierto, permanece abierto de momento que el establecimiento de criterios específicos para considerar una autonomía mínima no siempre es tan evidente como la pérdida de un yo anterior, como podría darse en un Alzheimer severo.

Conclusiones

La necesidad de autonomía que presenta el adolescente es necesaria para su buen desarrollo y, a su vez, también puede constituir una barrera en la búsqueda de ayuda para problemas de salud mental.

Distintos estudios que han buscado comprender las barreras para acceder a la atención profesional en salud mental han identificado como una de estas a la necesidad de autonomía o independencia que presentan los adolescentes y jóvenes.

Los padres pueden jugar un rol importante: por una parte, pueden contribuir al desarrollo de la autonomía en sus hijos adolescentes y, a su vez, serán de relevancia para que estos accedan a prestaciones de salud mental profesionales. El que los padres sean alfabetizados en temas de salud mental puede sin duda contribuir a que puedan distinguir de mejor manera cuando su hijo(a) adolescente requiere de atención en este ámbito y, a su vez, generar actitudes más positivas hacia la búsqueda de atención profesional en salud mental, contribuyendo a un mejor ejercicio de la autonomía y toma de decisiones en salud de parte de su adolescente.

A partir de los estudios revisados se considera recomendable que los profesionales de la salud mental tengan presente una perspectiva evolutiva en sus prestaciones con el grupo adolescente. Se debe tener muy presente que la necesidad de autonomía e independencia, propia de la etapa, puede por un lado contribuir a que el adolescente evite buscar ayuda o rechazar la que se le ofrezca.

Es deseable que los profesionales y educadores que trabajen con los jóvenes, ya sea en contexto educativo o de salud, aborden esta temática con ellos y sus padres, y que puedan a su vez implementar estrategias que apoyen la autonomía en el contexto de atención en salud mental, como ha sido evidenciado y recomendado en estudios previos*(53)*.

Es a partir de lo presentado que se destaca la relevancia de fomentar una discusión ética e integral respecto a la autonomía en la toma de decisiones de los adolescentes en el área del acceso a tratamiento y búsqueda de ayuda en salud mental. Un enfoque realista sobre la promoción de la autonomía en este ámbito abarcaría no solo la sensibilización de los adolescentes acerca de los recursos disponibles y el fomento de una actitud proactiva hacia esta ayuda disponible y los canales que puedan facilitarla, sino también promovería un rol activo y de apoyo por parte de los adultos en su entorno, con las observaciones pertinentes para reducir los efectos contraproducentes que estos actores puedan tener para los adolescentes. Este enfoque no solo optimizaría la búsqueda de ayuda cuando sea necesaria, atendiendo las mismas necesidades adolescentes de autonomía, sino que también favorecería el proceso de crecimiento personal del adolescente, contribuyendo al desarrollo de habilidades de búsqueda de ayuda y toma de decisiones a lo largo de esta etapa de desarrollo, y generando efectos positivos en etapas futuras.

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HISTORICAL ANALYSIS OF THE CONTRIBUTION OF PUBLIC POLICIES TO THE HUMANIZATION OF THE HEALTHCARE SYSTEM IN CHILE

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Abstract: The objective of this research was to analyze the historical contribution of public policies to the humanization of the healthcare system in Chile between 2004 and 2024. The methodology was a historical analysis of official documents from the Ministry of Health and its dependent agencies. The results show progressive advances in the regulatory recognition and promotion of principles such as dignity, respect, empathy, and participation in healthcare, especially since the enactment of Law 20.584 in 2012. However, gaps remain in implementing these policies, related to staff training, infrastructure, process adequacy, patient empowerment, and control systems. It is concluded that public policies have played a crucial role in establishing humanization as a central axis of the Chilean health system over the last two decades. It is recommended that mechanisms for enforcing rights be strengthened, training in relational skills intensified, a person-centered model be moved toward, resources for its implementation should be allocated, intersectoral initiatives coordinated, and research should be encouraged.

Keywords: humanization, public policies, health system, Chile

Análisis histórico de la contribución de las políticas públicas en la humanización del sistema de salud en Chile

Resumen: El objetivo de esta investigación fue analizar la contribución histórica de las políticas públicas en la humanización del sistema de salud en Chile entre los años 2004 y 2024. La metodología utilizada fue un análisis histórico de documentos oficiales del Ministerio de Salud y sus organismos dependientes. Los resultados muestran un avance progresivo en el reconocimiento normativo y la promoción de principios como la dignidad, el respeto, la empatía y la participación en la atención sanitaria, especialmente a partir de la promulgación de la Ley 20.584 en 2012. No obstante, persisten brechas en la implementación efectiva de estas políticas, relacionadas con la capacitación del personal, la adecuación de infraestructura y procesos, el empoderamiento de los pacientes y los sistemas de control. Se concluye que las políticas públicas han jugado un rol crucial en instalar la humanización como un eje central del sistema de salud chileno en las últimas dos décadas. Se recomienda fortalecer mecanismos de exigibilidad de derechos, intensificar la formación en habilidades relacionales, avanzar hacia un modelo centrado en las personas, asignar recursos para su implementación, articular iniciativas intersectoriales y fomentar la investigación.

Palabras clave: humanización, políticas públicas, sistema de salud, Chile

Análise histórica da contribuição de políticas públicas para a humanização do sistema de cuidados à saúde no Chile

Resumo: O objetivo dessa pesquisa foi analisar a contribuição histórica de políticas públicas para a humanização do sistema de cuidados à saúde no Chile entre 2004 e 2024. A metodologia compreendeu uma análise histórica de documentos oficiais do Ministério da Saúde e suas agências dependentes. Os resultados mostram avanços progressivos no reconhecimento regulatório e na promoção de princípios tais como dignidade, respeito, empatia e participação nos cuidados à saúde, especialmente desde a promulgação da Lei 20.584 em 2012. Entretanto, restam lacunas na implementação dessas políticas, relacionadas ao treinamento das equipes, infraestrutura, adequação de processos, empoderamento de pacientes e sistemas de controle. Concluiu-se que as políticas públicas tiveram um papel crucial em estabelecer a humanização como um eixo central do sistema de saúde do Chile nas duas últimas décadas. Recomenda-se que os mecanismos para reforçar direitos seja fortalecido, o treinamento de habilidades relacionais intensificado, um modelo centrado na pessoa seja impulsionado, recursos para sua implementação devem ser alocados, iniciativas intersetoriais coordenadas e pesquisa deve ser encorajada.

Palavras-chave: humanização, políticas públicas, sistema de saúde, Chile

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Introducción

La humanización de la salud se ha convertido en un enfoque central en los debates sobre la reforma y mejora de los sistemas de salud a nivel global*(1)*. Este enfoque busca trascender la visión tradicionalmente biomédica y crecientemente tecnologizada de la medicina, para enfatizar la importancia de una atención centrada en las personas*(2)*, reconociendo su dignidad, autonomía y necesidades integrales. En este contexto, las políticas públicas desempeñan un papel fundamental en la promoción y consolidación de prácticas humanizadas en los servicios de salud.

En Chile, el sistema de salud ha experimentado transformaciones significativas desde la década de los 90, impulsadas por una serie de reformas orientadas a mejorar la equidad, calidad y eficiencia en la prestación de servicios, como la Ley 20.584 (Derechos y deberes que tienen las personas en relación con acciones vinculadas a su atención de salud"), la Ley 19.664, que crea el sistema de Garantías explícitas de Salud, entre otras*(3)*. Estas reformas han abordado desafíos estructurales y han buscado responder a las demandas cambiantes de la sociedad. Sin embargo, la incorporación efectiva de los principios de humanización en la práctica cotidiana de los equipos de salud sigue siendo un desafío complejo y multidimensional.

Esta investigación se fundamenta en la premisa de que las políticas públicas son herramientas poderosas para moldear las prácticas y la cultura organizacional dentro del sistema de salud*(4)*. Por lo tanto, comprender cómo estas políticas han abordado la humanización a lo largo del tiempo puede proporcionar insumos valiosos sobre los avances logrados, las brechas persistentes y los desafíos futuros en la consolidación de un modelo de atención verdaderamente humanizado.

La humanización ha emergido como un paradigma transformador en el ámbito de la salud, desafiando los enfoques tradicionales centrados en la enfermedad y la incorporación de nuevas tecnologías*(5)*. Este concepto engloba una amplia gama de principios y prácticas que buscan reconocer y responder a las necesidades físicas, emocionales, sociales y espirituales de los pacientes, así como promover su autonomía, dignidad y participación en el proceso de atención*(6)*.

La literatura académica ha destacado consistentemente los beneficios de la humanización en la atención de las personas. Estudios han demostrado que las prácticas humanizadas se asocian con mejores resultados clínicos, mayor adherencia al tratamiento, reducción del estrés y ansiedad en los pacientes, y una mayor satisfacción tanto para los usuarios como para los profesionales de la salud*(7-9)*. Además, la humanización ha sido señalada como un factor clave para mejorar la eficiencia y sostenibilidad de los sistemas de salud, al promover un uso más racional de los recursos y reducir los costos asociados a complicaciones evitables*(8)*, así como también promover la resiliencia del sistema de salud.

En el contexto chileno, la humanización de la atención en salud ha ganado creciente relevancia en las últimas décadas. Las demandas sociales por un sistema de salud más equitativo, accesible y centrado en las personas han impulsado una serie de reformas y políticas públicas orientadas a mejorar la calidad y humanizar los servicios de salud*(11)*. Sin embargo, la implementación efectiva de estos principios no ha sido fácil, enfrentando múltiples desafíos que incluyen desde limitaciones presupuestarias, sobrecarga del sistema, resistencia al cambio organizacional, aumento de la diversidad cultural y brechas en la formación y capacitación de los equipos de salud*(12)*, hasta un sistema de acreditación creado para evaluar a los prestadores de salud que, en su desarrollo regulatorio posterior (estándares y manuales de acreditación), no contempló explícitamente la humanización en salud.

El sistema de salud chileno se caracteriza por contar con algunas particularidades que es necesario considerar al momento de analizar las políticas públicas en salud, ya que está compuesto por un sistema mixto de atención, integrado por el Fondo Nacional de Salud (FONASA), organismo público y un subsistema privado, organizado con entidades denominadas ISAPRES o Instituciones de Salud Previsional que administran parte de las cotizaciones obligatorias de salud y financian las atenciones de salud de las personas afiliadas en redes de atención no integradas*(13)*. Adicional-mente la atención de salud de los trabajadores se administra y gestiona a través de mutualidades, tres instituciones privadas sin fines de lucro y una estatal, que se financian con un seguro social de accidentes y enfermedades profesionales.

La conformación de este sistema de salud también es criticada por la fragmentación que se produce entre los distintos subsistemas, que atienden a poblaciones con perfiles socioeconómicos y epidemiológicos diferenciados*(14)*. Pese al alcance o pretensión de aplicación con carácter general para todo el sector de las políticas analizadas, esta estructuración fragmentada genera inequidades en el acceso y calidad de la atención, que pueden incidir en la experiencia de humanización percibida por los usuarios. En este contexto, el desafío es lograr articular e integrar el sistema de salud, poniendo al centro a las personas, sus familias y las comunidades. Es así como hace unos años se comienza a trabajar en la implementación de la “Estrategia de Redes Integradas del servicio de Salud en el sistema público (RISS)”, cuyo propósito es abordar la fragmentación de la Red Asistencial y cuyos pilares conceptuales son: Enfoque de Derechos, el Modelo de Salud Familiar y Determinantes Sociales de la Salud, abordando ámbitos estratégicos de la acción sanitaria integral para comprender la complejidad del bienestar de las personas y sus comunidades*(15)*.

En tal sentido, el sistema de salud chileno viene realizando esfuerzos desde hace ya bastantes años, incorporando al modelo de atención el carácter de integral, familiar y comunitario*(16)*, considerando las demandas ciudadanas y constituyéndose en un modelo de relación y cuidado continuo e integral entre las personas y familias con su entorno y los equipos de salud, permitiendo a la red sanitaria responder de manera oportuna, eficiente y eficaz para recuperar el estado de bienestar*(17)*.

A pesar de los esfuerzos realizados, aún hay barreras como la sobrecarga laboral, la falta de tiempo para la interacción con los pacientes, la fragmentación de los servicios y la persistencia de actitudes paternalistas entre los profesionales de la salud*(18,19)*. Estos hallazgos subrayan la necesidad de un análisis crítico y sistemático de las políticas públicas implementadas, con el fin de identificar fortalezas, debilidades y oportunidades de mejora. Además, sugieren que aún persisten desafíos significativos para la plena integración de la humanización en el sistema de salud chileno.

Este artículo tiene como objetivo realizar un análisis histórico de la contribución de las políticas públicas en la humanización del sistema de salud en Chile .

Metodología

Este estudio adopta un enfoque de análisis documental histórico, en el cual, a través de una revisión narrativa de documentos oficiales, informes gubernamentales y otros materiales relevantes, busca trazar la evolución de las políticas de salud en Chile respecto de la humanización. Este diseño permite una comprensión de los principios, valores, medidas e hitos propuestos en las normativas desde el punto de vista de la humanización de la salud en los últimos 20 años, debido a la última gran reforma de salud en Chile, las Garantías Explícitas en Salud de 2004*(20)*.

Criterios de selección

Se aplicaron criterios de inclusión y exclusión para seleccionar documentos pertinentes al estudio: a) documentos oficiales del Ministerio de Salud y sus organismos dependientes; b) publicados entre los años 2004 y 2024; c) que abordan directa o indirectamente aspectos de humanización de la salud. Los documentos incluidos son aquellos que directamente discuten, implementan o regulan las políticas de salud que contemplan en alguna medida la humanización y el trato a las personas. Entre estos se incluyen leyes, reglamentos, normas técnicas, circulares y otros documentos sectoriales. Se excluyeron todos los documentos publicados previamente a 2004 y aquellos que no fueron elaborados por un organismo gubernamental del sector salud.

Proceso de análisis

Para el proceso de recolección y análisis de información se utilizaron las estrategias de la revisión narrativa y el análisis documental, tomando en consideración la experiencia de los autores*(21)*. La evaluación de los documentos seleccionados se llevó a cabo a través de técnicas de análisis de contenido cualitativo. Dicho análisis implicó la codificación temática de los textos por parte de tres expertos en el área, para extraer patrones, temas y tendencias significativas respecto de la evolución de la humanización en las políticas sanitarias*(22)*. Se dio especial énfasis a la detección de principios y valores fundamentales, y a las medidas o hitos legislativos que han contribuido de manera significativa a la humanización del sistema sanitario en Chile. Basándose en estos principios e hitos se identificaron distintas etapas en la evolución legislativa, enfocadas en incorporar aspectos de humanización en los servicios de salud y sus principios rectores.

Resultados

Se identificaron y revisaron un total de 77 documentos relacionados con las políticas públicas de salud en Chile desde 2004 hasta la actualidad. Tras aplicar los criterios de inclusión y exclusión, se seleccionaron 69 documentos con los que se realizó una descripción por años y tipo de documento (gráfico 1) y, dentro de éstos, 19 documentos fueron analizados cualitativamente por su relevancia y aporte a la humanización, a través de cambios en el tiempo, su información rica y descriptiva, además de la experiencia de sus participantes*(23)* y con relación a los principios de humanización más relevantes encontrados en dichos documentos (tabla 1).

La humanización de la salud en Chile ha sido un proceso gradual pero sostenido en las últimas dos décadas, impulsado por un marco legal y normativo cada vez más robusto y centrado en la dignidad y derechos de las personas. En el gráfico 1, se observa que la mayoría de los documentos publicados corresponden a leyes (n=45), seguidas de resoluciones administrativas (n=19) y reglamentos (n=4). La actividad legislativa varió de un año a otro, con algunos años destacados como 2021 (11 documentos), 2012 (8 documentos) y 2020 (7 documentos). Por otro lado, hubo años con una actividad mínima, como 2004, 2008, 2010, 2014 y 2018, con solo un documento emitido en cada uno.

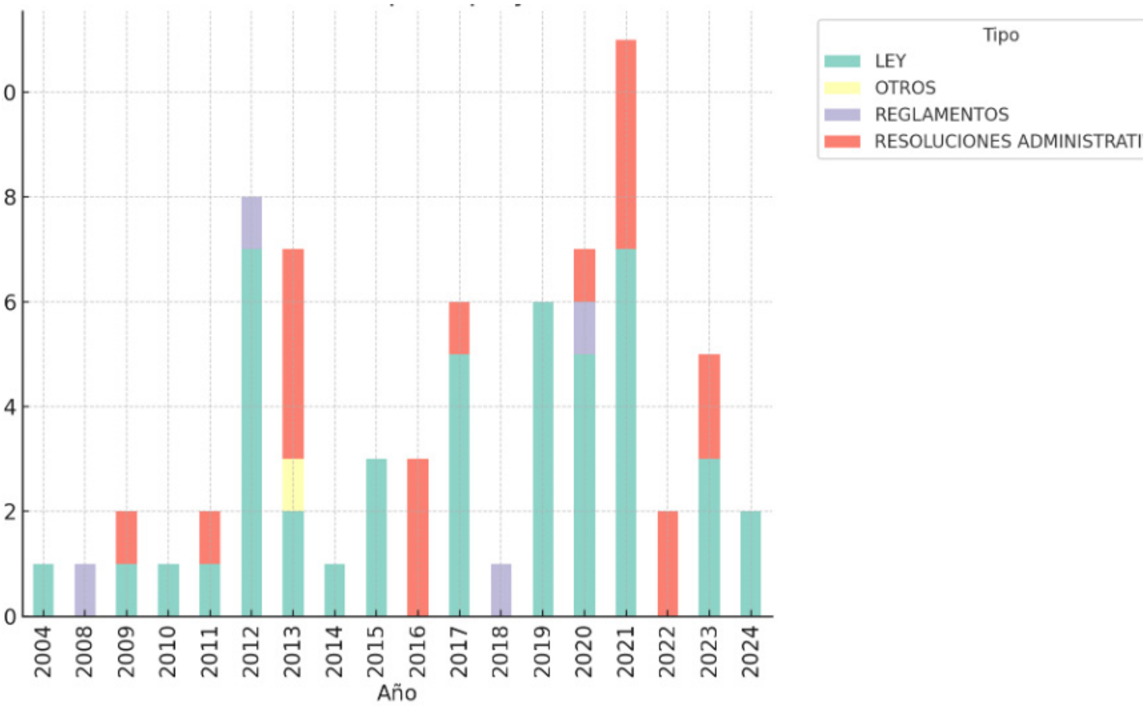

Gráfico 1. Documentos según tipo y año de publicación.
Nota: número de documentos según tipo y año de publicación. En la categoría "otros" se incluyen orientaciones técnicas del MINSAL.

Tabla 1. Resumen de los documentos según año, tipo y principios relacionados a la humanización

Etapa	Documento	Año	Descripción	Principios relacionados a la humanización
Etapa 1 (2004-2011): Sentando las bases de la humanización	Ley 19.966: Régimen GES, garantías exigibles, cobertura gastos catastróficos, responsabilidad sanitaria.	2004	Establece garantías explícitas en salud para un conjunto prioritario de problemas, asegurando acceso, calidad, protección financiera y oportunidad en la atención médica.	Acceso universal, atención de calidad, protección financiera, oportunidad, priorización, participación, transparencia y exigibilidad de derechos.
	Decreto 94: Reglamento asistencia religiosa en hospitales, respetando la libertad de creencia.	2008	Define condiciones para la asistencia religiosa en hospitales, respetando la libertad de creencia de los pacientes.	Libertad de creencias, no discriminación, respeto a voluntad del paciente y confidencialidad en asistencia religiosa.
	Ley 20379: Sistema Protección Social, subsistema "Chile Crece Contigo" para niños vulnerables.	2009	Institucionaliza un sistema de protección integral a la infancia para acompañar su desarrollo desde la gestación hasta los 18 años, destinado a la población más vulnerable socioeconómicamente.	Protección social focalizada, acción intersectorial, acompañamiento personalizado, fomento lactancia y acceso preferente a servicios.
	Ley 20422: Igualdad de oportunidades e inclusión de personas con discapacidad.	2010	Asegurar el derecho a la igualdad de oportunidades y la plena inclusión social de las personas con discapacidad, abordando diversos ámbitos como la prevención, accesibilidad, educación e inclusión laboral.	Igualdad de oportunidades, inclusión, vida independiente, accesibilidad universal, diseño universal, intersectorialidad, participación, no discriminación, respeto y autonomía personal.
	Circular 34: Atención personas trans, estrategia Hospital Amigo, no discriminación.	2011	Instruye sobre la atención de personas trans en servicios de salud, buscando mejorar su acceso y equidad en la atención sanitaria.	Equidad, derechos humanos, no discriminación, respeto a identidad de género, acceso oportuno y atención integral.
	Ley 20.545: Permiso postnatal parental, extensión a padres, subsidio, fuero maternal.	2011	Modifica normas sobre protección a la maternidad e incorpora un permiso postnatal parental, otorgando subsidios y fuero maternal.	Protección a maternidad e infancia, corresponsabilidad parental, no discriminación y conciliación trabajo-familia.
Etapa 2 (2012-2016): Consagración legal de los derechos de las personas en su atención de salud.	Ley 20.584: Derechos y deberes en atención de salud, trato digno, autonomía.	2012	Establece principios para garantizar una atención digna, respetuosa y humanizada, así como deberes de los pacientes y mecanismos de reclamo.	Dignidad, no discriminación, trato humanizado, privacidad, autonomía, información, participación, pertinencia cultural, protección grupos vulnerables, calidad y seguridad.
	Decreto 38: Reglamento Ley 20.584, regula derechos y deberes de pacientes.	2012	Crea un fondo especial para cubrir financieramente diagnósticos y tratamientos de alto costo, asegurando su acceso para todos los beneficiarios de los sistemas de salud.	Atención oportuna sin discriminación, acceso para discapacidad, seguridad y calidad, privacidad, autonomía, protección derechos y participación usuaria.
	Decreto 31: Reglamento sobre consentimiento informado y entrega de información en salud.	2012	Presenta lineamientos para promover un trato digno, inclusivo y humanizador en la atención de salud, buscando mejorar la calidad y satisfacción usuaria.	Derecho a ser informado, consentimiento libre, confidencialidad, autonomía del paciente y deber de informar del profesional.
	Ley 20.850 "Ricarte Soto": Cobertura financiera	2015	Crea un Sistema de Protección Financiera para Diagnósticos y Tratamientos de Alto Costo en Chile,	Protección financiera, equidad en acceso, priorización técnica, participación, transparencia y exigibilidad.

	tratamientos de alto costo.		cubriendo financieramente ciertos diagnósticos y tratamientos.	
	Orientaciones Técnicas sobre “Buen Trato”: Lineamientos de trato digno e inclusivo en salud.	2016	Promueve un trato digno, inclusivo y humanizador en la atención de salud en Chile, buscando mejorar la calidad y satisfacción del usuario.	Salud como derecho, enfoque inclusivo, participación, corresponsabilidad, equidad, satisfacción usuaria, trato digno, legitimidad, calidad, oportunidad y gestión abierta.
	Ley 21.030: Despenaliza aborto 3 causales (riesgo vital, inviabilidad fetal, violación).	2017	Regula el acceso al aborto en casos de riesgo vital para la mujer, inviabilidad fetal y embarazo producto de violación, estableciendo requisitos y procedimientos.	Autonomía de la mujer, no discriminación, confidencialidad, información veraz, acompañamiento integral, cuidados paliativos, capacidad de niñas y protección derechos.
Etapa 3 (2017 en adelante): Profundización y especificación de la humanización	Ley 21.063: Seguro SANNA para padres de niños con enfermedades graves.	2017	Permite a padres y madres trabajadores ausentarse del trabajo para cuidar a sus hijos enfermos, recibiendo un subsidio.	Protección de la infancia vulnerable, conciliación trabajo-familia, solidaridad en financiamiento, universalidad y equidad de género.
	Ley 21.258 “Ley Cáncer”: Plan Nacional, no discriminación, derecho al olvido.	2020	Establece un marco normativo para prevenir y tratar el cáncer, creando un plan nacional, una comisión y un fondo, además de prohibir la discriminación laboral por esta enfermedad.	Cooperación público-privada, protección de datos, participación sociedad civil, humanización, atención integral, acceso equitativo y evidencia científica.
	Ley 21.380: Atención preferente en salud a cuidadores de personas dependientes.	2021	Reconoce el derecho a atención preferente en salud a cuidadores, ampliando el acceso a este beneficio.	Reconocimiento cuidadores, equidad en acceso y dignidad en trato a cuidadores.
	Ley 21375: Derechos y cuidados paliativos para enfermedades terminales o graves.	2021	Reconoce y regula el derecho a una adecuada atención de salud para pacientes en situaciones terminales o graves, priorizando el cuidado integral y los cuidados paliativos.	Acceso sin discriminación, cuidado integral, respeto dignidad y autonomía, y consideración de la muerte como ciclo vital.
	Ley 21.331: Derechos de personas con enfermedad mental o discapacidad psíquica.	2021	Reconoce y protege los derechos fundamentales de las personas con enfermedad mental o discapacidad psíquica o intelectual.	Reconocimiento integral, respeto dignidad/autonomía, igualdad, promoción salud mental, participación, respeto desarrollo niños, equidad, derecho a vida independiente y accesibilidad.
	Ley 21.300: Amplía donación de órganos entre vivos (parientes y convivientes civiles).	2021	Amplía la posibilidad de donación entre vivos, incluyendo parientes por afinidad y convivientes civiles como potenciales donantes.	Ampliar donación en vida, reconocer vínculos afectivos, asegurar voluntariedad y gratuidad, y promover transparencia.
	Ley 21656: Derecho al olvido oncológico	2024	Prohíbe la discriminación basada en el historial oncológico una vez transcurridos cinco años desde la finalización exitosa del tratamiento sin recaídas	Dignidad del paciente, igualdad y no discriminación, privacidad y confidencialidad, y acceso a servicios sin barreras por historial oncológico.

Nota: Fuente, Biblioteca del Congreso Nacional de Chile / BCN (www.bcn.cl/leychile/)

A partir del análisis de las principales leyes y regulaciones, es posible distinguir tres grandes etapas del marco normativo y los principios que sustentan la humanización en Chile:

Etapa 1 (2004-2011): Sentando las bases de la humanización

En este periodo inicial, si bien no existía aún una legislación específica sobre derechos de los pacientes, comenzaron a surgir iniciativas y normativas administrativas orientadas a mejorar la calidad y calidez de la atención. Destaca la ley que estableció el Régimen de Garantías Explícitas en Salud (AUGE/GES, 2004), asegurando acceso, oportunidad y protección financiera para un conjunto priorizado de problemas de salud. Aunque su foco era más bien de cobertura, esta reforma introdujo la noción de derechos exigibles y situó las necesidades de las personas en el centro del debate público sobre las políticas de salud. También podemos destacar varias otras iniciativas que fueron consagradas en este periodo, tales como la ley que creó el Sistema Intersectorial de Protección Social Chile Crece contigo (2009), la ley sobre igualdad de oportunidades e inclusión de personas con discapacidad (2010), la que fijó normas sobre información, orientación y prestaciones en materia de regulación de la fertilidad (2010), y la que extendió el periodo de posnatal (2011).

También en esta etapa se publicaron orientaciones ministeriales para favorecer el acompañamiento, el trato digno y la participación de los usuarios, como el Manual de “Hospital Amigo” (2007), la Norma General de Participación Ciudadana en la Gestión Pública de Salud (2010), el Reglamento sobre Asistencia Religiosa en Recintos Hospitalarios (2008) y la circular sobre atención de personas trans (2011). Si bien acotadas en su alcance jurídico, estas normas técnicas fueron pavimentando el camino para una atención más humana y empática; facilitando que las primeras iniciativas legales destinadas a consagrar un catálogo de derechos del paciente, presentadas entre los años 2000 y 2001, se transformaran en ley en el año 2012.

Durante este periodo se sientan las bases de la humanización del sistema de salud en Chile, ya que se introduce la noción de derechos exigibles por parte de las personas en su atención de salud, así como otras normativas que complementan la implementación y respeto de estos principios, como son el acceso a la atención, la oportunidad y protección financiera, el respeto a las creencias culturales y religiosas y decisiones de las personas sobre su salud. Estos esfuerzos impulsaron un cambio en el modelo de atención, hacia uno más humano, integral, inclusivo y respetuoso con los derechos y necesidades de las personas.

Etapa 2 (2012-2016): Consagración legal de los derechos de las personas en su atención de salud

En 2012 se produce un hito relevante para la humanización en salud con la publicación de leyes que impactan directamente en el trato digno y respetuoso de las personas como sujetos de derechos y deberes en el sistema de salud chileno.

Un hito clave que marca el inicio de esta segunda etapa es la promulgación de la ley que regula los derechos y deberes de las personas en su atención de salud (2012). Esta normativa establece un marco general para garantizar un trato digno, el respeto a la autonomía y privacidad, el acceso a la información, el consentimiento informado y el derecho al acompañamiento, entre otros. Además, mandata a los prestadores a establecer mecanismos de participación y reclamo para los usuarios del sistema.

La ley de derechos y deberes cambió el paradigma al explicitar que los pacientes son sujetos de derechos y que estos deben ser respetados en toda atención sanitaria. A partir de este nuevo marco, se dictaron reglamentos y normas técnicas para operacionalizar estos derechos, como el Reglamento sobre Entrega de Información y Expresión de Consentimiento Informado (2012), el Reglamento sobre Derechos y Deberes de las Personas en Atención de Salud (2012) y las Orientaciones Técnicas sobre Trato Digno (2016), entre otros. Asimismo, en esta etapa, el sistema de garantías explícitas logró su consolidación sucesiva, incorporando nuevos problemas de salud y la entrada en vigor de la garantía de calidad (2013).

En este periodo también se aprobaron leyes relevantes para humanizar ámbitos específicos de la atención y mejorar la cobertura, como la ley que estableció una asignación especial asociada a la calidad del trato al usuario para trabajadores de la salud municipal (2012), la ley que creó un Sistema de Protección Financiera para Diagnósticos y Tratamientos de Alto Costo (2015), reduciendo el riesgo de empobrecimiento por gastos catastróficos en salud.

Estas medidas subrayan un cambio significativo hacia un modelo de atención más humano, que valora la dignidad y el bienestar integral de cada individuo al reconocer la salud como un derecho fundamental que involucra una responsabilidad colectiva, que promueve una relación más equitativa y colaborativa entre el equipo de salud, favoreciendo la atención de grupos vulnerables o tradicionalmente postergados. Durante este periodo resulta claro el esfuerzo por avanzar tanto en mejorar la protección financiera como también en el reconocimiento explícito de derechos a las personas, el respeto de la dignidad del paciente, de su autonomía y de su derecho a la información.

Etapa 3 (2017 en adelante): Profundización y especificación de la humanización

Luego, entre 2017 y 2018, se avanzó hacia una "nueva etapa" en términos de humanizar el sistema de atención de los grupos más vulnerables. La aprobación de la ley de aborto en tres causales significó un hito en términos de movilización social, de apoyo transversal de esa política y el carácter simbólico de la consagración de los derechos de las mujeres en este ámbito.

En los siguientes años la legislación ha avanzado en profundizar y especificar la humanización de la atención sanitaria en diversos ámbitos y poblaciones. En esta etapa, una ley emblemática es la que establece un marco de protección de derechos de las personas con enfermedad mental, trastorno psiquiátrico o discapacidad intelectual (2021). Esta norma promueve un modelo comunitario y ambulatorio, con pleno respeto a la autonomía y las opciones de tratamiento, regulando prácticas coercitivas como la hospitalización involuntaria y el tratamiento forzoso. También destaca la ley SANNA, que creó un seguro para que padres y madres trabajadoras puedan ausentarse y cuidar a hijos con enfermedades graves, con un subsidio económico (2017). Esta iniciativa prioriza el bienestar familiar y el acompañamiento en situaciones de alta vulnerabilidad, humanizando el sistema de protección social. En tanto, la ley que garantiza el derecho a la prevención, tratamiento y cuidados paliativos del dolor buscó promover una atención integral del sufrimiento al final de la vida (2021). Otras normativas relevantes en esta etapa son la ley que modernizó el sistema de donación de órganos, equilibrando la disponibilidad de éstos con el respeto a la autonomía (2019); la ley nacional del cáncer (2020); la ley que amplió los programas de acompañamiento a madres vulnerables, con un enfoque biopsicosocial desde la gestación hasta la primera infancia (2021), y la ley sobre olvido oncológico, que busca disminuir barreras de acceso al sistema financiero a quienes han superado el cáncer (2024).

A través de estas leyes y políticas, el sistema de salud chileno ha profundizado en los principios de la humanización, ya que ha ido incorporando una mirada cada vez más integral del ser humano, que busca no solo acoger su dimensión física, mental, emocional y espiritual, sino también la dimensión social y comunitaria. Una mirada que reconoce a la persona en su globalidad, así como la experiencia de la enfermedad, el sufrimiento y la sanación como eventos que involucran procesos vitales profundos, y que requieren un entorno que favorezca el acompañamiento empático y respetuoso por parte de los equipos de salud.

Discusión

De lo descrito resulta claro que la evolución del proceso legislativo y normativo de Chile en materia de salud ha presentado importantes avances para efectos de humanizar el sistema, alternando esfuerzos legislativos que gozaron de transversal apoyo, con una constante producción reglamentaria y técnica destinada a los equipos de salud de la Red Asistencial Pública.

El análisis histórico de las políticas públicas de salud en Chile desde 2004 revela un proceso gradual pero sostenido de incorporación de los principios de humanización en el marco normativo y regulatorio del sistema sanitario. Este tránsito refleja un cambio de paradigma, en el que la dignidad intrínseca de las personas y el respeto a sus derechos han ido adquiriendo una centralidad creciente en el diseño e implementación de las políticas de salud. Otra revisión sistemática*(24)*, basada en las perspectivas ética y bioética de la humanización en salud, también había destacado el respeto por la integridad de las personas y una atención centrada en sus derechos y dignidad como un punto de partida fundamental. Esta centralidad de la dignidad necesitaba sustentarse en el reconocimiento y la creación de procedimientos continuamente basados en la reflexión ética. Destacando además que las instituciones de salud constituyen agentes relevantes en la promoción de estas prácticas humanizadoras.

La trayectoria descrita da cuenta de un proceso acumulativo, en el que cada etapa ha ido construyendo sobre los cimientos de la anterior. Desde iniciativas administrativas acotadas en los 2000, se avanzó hacia la consagración legal de los derechos de los pacientes en 2012, para luego profundizar y especificar la humanización en diversos ámbitos y poblaciones en los últimos años. Este recorrido incremental ha permitido permear progresivamente los principios de la atención centrada en la persona en los distintos niveles y espacios del sistema de salud.

Un hallazgo relevante es que la evolución normativa no solo ha reconocido la dimensión biomédica de la atención, sino que ha ido incorporando una mirada cada vez más integral del ser humano, que busca acoger sus necesidades emocionales, espirituales y sociales en regulaciones específicas sobre acompañamiento, cuidados paliativos, salud mental y apoyo a poblaciones vulnerables, entre otras. Esta ampliación del foco da cuenta de una comprensión creciente de que la experiencia de la enfermedad y la sanación involucran procesos vitales profundos, que requieren un abordaje holístico y empático, pero también de la irrupción de los pacientes como un actor protagónico, que exige ser reconocido como un interlocutor válido en las decisiones sobre su salud*(25)*, empoderando progresivamente a los usuarios, reconociéndolos como sujetos de derechos y promoviendo su participación activa en las decisiones sobre su salud. Mecanismos como el consentimiento informado, los reclamos y la participación ciudadana reflejan un giro hacia una relación clínica más horizontal y colaborativa, en la que los pacientes son interlocutores válidos y no meros receptores pasivos de indicaciones.

Sin embargo, es importante reconocer que la sola existencia de un marco legal propicio no garantiza *per se* la humanización efectiva de los cuidados. La brecha entre el texto de la ley y la vivencia cotidiana en los servicios de salud sigue siendo un desafío mayor. Factores como la sobrecarga laboral, la falta de tiempo, la precariedad de recursos y la persistencia de culturas organizacionales rígidas y biomédicas pueden obstaculizar la traducción de los principios normativos en un trato digno y empático*(18)*.

En este sentido, la genuina humanización demanda un cambio cultural profundo al interior de las instituciones sanitarias, que interpela a flexibilizar las lógicas burocráticas y administrativas para adaptarse a las necesidades únicas de cada persona y familia. Esto requiere estrategias de sensibilización, capacitación y acompañamiento continuo a los equipos de salud, así como una revisión de los incentivos, procesos y estructuras organizacionales*(7)*.

Otra discusión relevante que emerge de los resultados es la estandarización que promueven algunas políticas en materia de cuidados. Si bien las normativas generales sobre trato digno o derechos son imprescindibles, existe el riesgo de que su aplicación derive en protocolos rígidos que terminen “deshumanizando” la atención. El desafío es encontrar un equilibrio virtuoso entre criterios universales de calidad y la flexibilidad para adaptar la atención a la singularidad de cada encuentro humano. En síntesis, la trayectoria de humanización de la salud en Chile muestra una progresión desde iniciativas administrativas acotadas hacia un robusto marco legal de derechos en salud, que luego se profundiza en ámbitos específicos.

Conclusiones

El análisis histórico de las políticas de salud en Chile entre 2004 y 2024 revela una progresión consistente hacia la instalación de los principios de humanización en el marco regulatorio del sistema sanitario. A través de leyes y normativas específicas, el país ha ido reconociendo crecientemente la dignidad intrínseca de las personas y su derecho a una atención centrada en sus necesidades físicas, emocionales y sociales.

Este tránsito da cuenta de un cambio de paradigma, en el que el paciente ha dejado de ser un receptor pasivo de indicaciones médicas para convertirse en un sujeto de derechos y un interlocutor válido en las decisiones sobre su salud. Políticas clave, como la ley de derechos y deberes del paciente, las regulaciones sobre consentimiento informado y las garantías explícitas de acceso y calidad, han abonado el camino para una relación clínica más horizontal, empática y participativa.

Sin embargo, este estudio también revela que la existencia de un marco legal propicio es condición necesaria pero no suficiente para una genuina humanización de los cuidados. Factores como la sobrecarga laboral, la rigidez de los procesos y la persistencia de culturas biomédicas centradas en la enfermedad siguen obstaculizando la traducción de los principios normativos en un trato digno y empático en la vivencia cotidiana de los servicios de salud.

Los resultados permiten afirmar que las políticas públicas han jugado un rol crucial en instalar la humanización como un eje central del sistema de salud chileno en las últimas dos décadas. Sin embargo, el análisis también revela que este es un proceso en desarrollo, con avances promisorios, pero también con barreras y desafíos persistentes. Consolidar un modelo de cuidados genuinamente centrado en la persona requerirá profundizar las estrategias normativas con acciones decididas de gestión del cambio organizacional, formación de competencias relacionales en los equipos y éticas, junto con empoderamiento de los usuarios.

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THE SLIPPERY SLOPE PARADOX: WHEN RESTRICTING AUTONOMY FUELS DEMANDS FOR PHYSICIAN-ASSISTED DYING

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Abstract: Korea's system for end-of-life care and letting people die is quite rigid in the direction of maintaining life. The Life-sustaining Treatment Decision Act was enacted in 2016, but there was little opportunity for the breadth and depth of public discussion to develop before that. This paper aims to show the "concerns about the slippery slope" that some of the participants in the legislative debate had as one of the historical reasons for creating the conservative framework and detailed provisions of Korea's Life-sustaining Treatment Decision Act. Because of their arguments, the law was structured as a barricade to prevent slippery slopes. However, in 2022, the fifth year after the law took effect, a bill was proposed to legalize physician-assisted dying. This paper makes a worrisome prediction that this radical movement will continue unless it is possible to set treatment goals tailored to the patient's medical condition and values through the guarantee of the right to refuse treatment.

Keywords: self-determination, personal autonomy, assisted death, treatment refusals, refusal of treatment

¿ La paradoja de la pendiente resbaladiza: cuando restringir la autonomía alimenta las demandas de una muerte asistida por un médico

Resumen: El sistema coreano de cuidados paliativos y de abandono de la vida es bastante rígido en cuanto a la preservación de la vida. La Ley de Decisión sobre Tratamientos de Soporte Vital se promulgó en 2016, pero hubo pocas oportunidades para que el debate público se desarrollara con la amplitud y profundidad que se habían generado anteriormente. Este artículo pretende mostrar las preocupaciones sobre la pendiente resbaladiza que algunos participantes en el debate legislativo tuvieron como una de las razones históricas para crear el marco conservador y las disposiciones detalladas de la Ley de Decisión sobre Tratamientos de Soporte Vital de Corea. Debido a sus argumentos, la ley se estructuró como una barrera para evitar pendientes resbaladizas. Sin embargo, en 2022, cinco años después de su entrada en vigor, se propuso un proyecto de ley para legalizar la muerte asistida por un médico. Este artículo predice de forma preocupante que este movimiento radical continuará a menos que sea posible establecer objetivos de tratamiento adaptados a la condición médica y los valores del paciente mediante la garantía del derecho a rechazar el tratamiento.

Palabras clave: autodeterminación, autonomía personal, muerte asistida, rechazo al tratamiento, denegación del tratamiento

O paradoxo da inclinação escorregadia: quando restringir a autonomia alimenta as demandas de uma morte assistida por um médico

Resumo: O sistema coreano de cuidados paliativos e de deixarem as pessoas morrerem é bastante rígido no que diz respeito à manutenção da vida. A Lei de Decisão de Tratamento de Suporte à Vida foi promulgada em 2016 mas houve pouca oportunidade para que a amplitude e profundidade do debate público se desenvolvesse antes disso. Esse artigo objetiva demonstrar as "preocupações sobre a ladeira escorregadia" que alguns dos participantes na discussão legislativa tinham como uma das razões históricas para a criação do estrutura conservadora e das disposições detalhadas da Lei de Decisão de Tratamento de Suporte à Vida da Coréia. Devido aos seus argumentos, a lei foi estruturada para funcionar como uma barreira para evitar descaminhos. Entretanto, em 2022, o quinto ano após a lei entrar em vigor, foi proposto um projeto de lei para legalizar a morte assistida por médicos. Esse artigo faz uma previsão preocupante de que esse movimento radical continuará a menos que seja possível estabelecer metas de tratamento adaptadas à condição médica e valores do paciente por meio da garantia do direito de recusar tratamento.

Palavras-chave: autodeterminação, autonomia pessoal, morte assistida, recusa do tratamento, negação do tratamento

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Introduction

South Korea's system for end-of-life care and letting people die is heavily weighted in favor of keeping people alive. Although the Act on Hospice and Palliative Care and Decisions on Life-Sustaining Treatment for Patients at the End of Life*(1)*, AKA Life-Sustaining Treatment Decision Act, was enacted in 2016 with the purpose of "to protect the dignity and value of human beings by assuring the best interests of the patients and by respecting their self-determination*(1)*" and has been in force since 2018, the freedoms guaranteed by the Act are minimal. The law defines the time for refusal of treatment as the end-of-life process, "a state of imminent death, in which there is no possibility of revitalization or recovery despite treatment, and symptoms worsen rapidly*(1)*," and lists treatments that can and cannot be withdrawn at this point. The right to refuse treatment is nowhere explicitly declared in law or case law. This silence, when interpreted in conjunction with legal provisions regarding the scope of treatment withdrawal and withholding, would have likely limited the number of patients able to refuse aggressive treatments.

Historically, there have been relatively few cases in Korea on end-of-life care and dying or letting die compared to other countries. As a result, the breadth and depth of public discussion have had fewer opportunity to develop. Death has been medicalized, and as once-functional communities of family, lineage, belief, religion, and local neighborhoods have disappeared, many aspects of dying that were once managed by these communities have now become the responsibility of professionals. As a result, the process of dying has become a complex issue, understood by only a small group of healthcare professionals, to the extent that even doctors require detailed explanations to fully grasp it. Legislative discussions and draft laws were organized around experts and a few "representatives" without broad public awareness or participation, and transparent and efficient discussion structures to make this possible. In the absence of a social consensus, the outcome of the legislative discussion largely mirrored the structure of the previous judicial precedent*(2)*, resulting in legislation that failed to recognize the right of patients to self-determination, the appointment of a surrogate, and the active role of hospital ethics committees*(3)*.

Meanwhile, in 2022, five years after the law came into effect, a bill was proposed to legalize physician-assisted dying*(4)*. Although the bill was proposed as an amendment to the Life-Sustaining Treatment Decisions Act*(1)*, it diverged too much from the direction and scope of the current law, faced opposition from various groups, and ultimately was not passed. However, this should not be dismissed as an isolated incident. The conservative approach taken by the legislative debate, the unmet needs it leaves behind, and the limitations of the legislation could lead to similar demands in the future.

This paper examines the current state of South Korea's institutions concerning end-of-life care, with a particular focus on the "slippery slope" concerns expressed by some participants in the legislative discussions. These concerns are identified as one of the historical reasons for the conservative framework and detailed provisions of the Life-Sustaining Treatment Decisions Act. Due to these arguments, the law has been structured as a barricade against the slippery slope. It is crucial to assess whether the cautious approach they advocated was appropriate for Korean society. Additionally, given the government's lack of proactive commitment to improving end-of-life care and palliative care, the law may have inadvertently created significant risks, which are already becoming apparent. The following circumstances illustrate these risks: an increasing number of people being denied appropriate end-of-life care; patients enduring disproportionate suffering from harmful treatments to remain within the healthcare system and avoid abandonment; the profession being engaged in ethically questionable practices; and growing distrust in the patient-physician relationship. These risks are not inevitable; rather, they stem from the excessive fear of the consequences of a patient's right to refuse treatment, resulting in an extreme limitation of that right. In other words, in attempting to avoid the slippery slope, the law may be pushing people towards a far more extreme scenario—heading towards a cliff.

Historical Development of the Barricade Against the Slippery Slope

The discussion of this law in Korea has a relatively short history. The first case in which the termination of treatment drew public's attention was the Boramae Hospital case. This case occurred in 1997, and the Supreme Court ruled in 2004*(5).* Contrary to public and physician misconceptions at the time, this is not a case of patient refusal of treatment. This is a case where the patient's wife refused treatment and the patient was discharged from the hospital, resulting in the patient's death, in a situation where the patient had lost decision-making capacity and would have benefited from treatment. Since the Supreme Court ruling that sentenced doctors to prison, the medical community has continued to overtreat patients with no hope of recovery, out of fear of punishment. It was only after a 2009 Supreme Court ruling that allowed doctors to withdraw ventilator treatment on the presumption of wishes of a patient who "is considered to have entered the irreversible stage of death*(2)*" that the movement to enact legislation became apparent. Even after the Constitutional Court's decision, which indicated that the state was not obligated to legislate*(6)*, and even though the majority opinion from the social consultative body established by the Ministry of Health and Welfare*(7)* was that legislation was unnecessary, discussions about the need to enact a special law continued. In response to these societal demands, the special committee of the National Bioethics Committee drafted a recommendation that would later evolve into a legislative proposal. The National Bioethics Committee then reviewed and approved this recommendation*(8,9).* Unlike the United States, which has accumulated more than 100 cases over the past 25 years from In re Quinlan to Cruzan v. Director, Missouri Department of Health *(10,11,12),* Korea has only had one case on refusal of life-sustaining treatment. The jurisprudence of the Supreme Court decision was not further elaborated or communicated understandably to professionals and the public, and public understanding of the issue did not deepen between 2009, when the Supreme Court decision was issued, and 2014 and 2015, when legislation was proposed. Refusal of treatment was often ambiguously described using terms like 'death with dignity,' 'euthanasia,' and sometimes even 'suicide.' The right to refuse treatment was rarely asserted by patients or the public.

In this situation, the legislative discussions were limited to a small number of 'representatives' and 'experts.' After the Supreme Court's ruling, the group that recommended the special law and drew up the core framework for the later drafting was the social consultative body established by the Ministry of Health and Welfare*(7).* It was comprised of 18 members including the former deputy minister of health and welfare and representatives from the religious, medical, legal, civil society, and legislative sectors. After meeting seven times in seven months, the consultative body announced the results of its discussions on which patients may be withdrawn from life-sustaining treatment and the scope of life-sustaining treatment that could be withdrawn. The minutes of the discussions were not publicly available at the time and have not been released since. A year and a half after the announcement, the National Bioethics Committee formed a special committee to discuss the institutionalization of futile life-sustaining treatment withdrawal for six months and established the results as recommendations for end-of-life decisions*(9,13).* The committee had 11 members, including six who had participated in the previous social consultative body. Same as in the previous consultative body, the members were not elected and their deliberations were not publicized in real time.

It is noteworthy that in this discussion structure, participants representing the religious community gained significant influence. Of the 18 members of the council, there were four representatives from the religious community, representing Protestants, Catholics, Buddhists, and Won-Buddhists, respectively. It is also noteworthy that people who are unable to form any organized social group—for example, those who are non-religious or atheists—were not eligible to nominate representatives, and that some of the civil society representatives who did not represent a religion also had an affinity with a particular religion. Representatives from both the Catholic and Protestant churches appear to have had strong opinions on narrowing the scope of withdrawal of treatment*(14).* Specifically, they insisted on the exclusion of PVS patients from treatment withdrawal and the designation of only terminally ill patients as eligible for treatment withdrawal. They also rejected the presumption of patient wishes to withdraw treatment and the designation of proxy. This position persisted in subsequent discussions, resulting in the final law limiting treatment withdrawal or withholding to the time period of the end-of-life process and not providing the option of designating a surrogate. Given the strong Catholic and Protestant opposition to the arbitrary termination of human life, it is unlikely that full recognition of the right to refuse treatment was discussed at the meetings.

As the minutes of the meeting are not publicly available, there is no way to know what the discussions within the meeting consisted of and what arguments were made. However, based on the context, it is possible to speculate on the origin of the arguments for limiting the scope of treatment refusal or the restriction on surrogate decision making. First of all, it is unlikely that it came from representatives of the medical community. In the first place, the medical community was asking for legislation for use in practice and for physicians to be free from the risk of legal penalties. Given that the previous guideline*(15)* developed by medical professional organizations, including medical associations, before this meeting included treatment withdrawal for PVS patients, it is unlikely that the medical community intended to severely limit the scope of treatment withdrawal.

On the other hand, the arguments of the Catholic and Protestant representatives on the Council are articulated in several of their own publications. They argue that a patient's right to self-determination cannot be absolute, and that the risks of self-determination can be real. Notably, they both cautioned against refusal of treatment based on self-determination, citing the "slippery slope*(16)*" or "slippery ladder theory*(17)*." Kyo Hun Chin, who represents the Catholic community, is even wary of self-determination being used as a basis for withdrawing life-sustaining treatment, saying "I would like to discuss the problem of the patient's right to self-determination in the legislating withdrawal of life-sustaining treatment. It is because once the decision to withdraw life-sustaining treatment is based on the patient's right to self-determination, what will follow is the risk that this will later be inferred and expanded to include the patient's right to arbitrarily refuse certain treatments and to decide on their own death. If the right to self-determination is used to determine human life and death, this could lead to the permissibility of euthanasia and suicide*(17)*." Here he is concerned that the right to self-determination is used as a basis for "arbitrarily refusing" medical treatment that is not life-sustaining treatment--what he calls "certain treatments"--and that this could lead to the permissibility of euthanasia and suicide.

Similarly, Lee Sang-won, a representative of the Protestant community, seeks to correct the understanding of his fellow scholars to distinguish between withdrawal of futile medical treatment and passive euthanasia, and his premise is that only when there is a combination of "not artificially terminating life but allowing death to come naturally" and the patient's explicit expression of wishes to do so —which he defines as withdrawal of futile medical treatment and which Korean current law defines as withdrawal of life-sustaining therapy — is it justifiable*(14)*. This is consistent with his opposition to the institutionalization of withdrawal of life-sustaining treatment, stating that "human life belongs to God and is not a matter of human nature*(18,19)*." In response to this opinion of some members of the consultative body, the scope of the right to self-determination was limited in the subsequent drafting process. Subsequently, the Special Committee of the National Bioethics Committee*(13)* revised the term 'terminal patient' to 'end-of-life' or 'dying process' to avoid broad interpretations, and explicitly excluded patients in a persistent vegetative state (PVS). After reviewing the recommendations of this Special Committee, the National Bioethics Committee stated that the scope of self-determination should be specifically defined in the context of life-sustaining treatment decisions*(13)*, and did not discuss the general rights of self-determination regarding any treatment.

This position of the religious community, especially the Catholic Church, was reiterated at a public hearing on the draft law by parliamentarian Kim Jae-won who received the draft of the National Bioethics Committee, and presented as the "Draft

Law on Decisions on Life-Sustaining Treatment for Patients at the End of Life*(20).*" Father Jung Jae-woo, who participated as a panelist, recommended postponing the enactment of the law until the laws and policies on hospice and palliative care are sufficiently developed, and not providing advance directives that can be written without a conversation with a doctor, even in the absence of illness. Instead, he recommended to provide a Life-Sustaining Treatment Plans, equivalent to Physician Orders for Life-Sustaining Treatment (POLST), only. The reason he made such a claim was likely due to his concern that the passing of the bill could "deepen a culture of devaluing life, or a culture of death*(21).*"

In a pluralistic society, it is natural to have differing opinions about what good can be achieved at the end of human life, what support should be provided by those at the bedside and by the medical profession, what are the expected consequences of institutionalizing and implementing such support, and how to evaluate those consequences. The question is how supporters of "incompatible yet reasonable comprehensive doctrines*(22)*" can come together to reach a consensus on direction and terms and translate that consensus into law. Unfortunately, the legislative discussions aimed at creating end-of-life legislation in South Korea have demonstrated that, at least in matters of human life and death, individuals with differing belief systems cannot achieve the ideal of "overlapping consensus*(22)*". Instead, what emerged was a negotiated compromise. When evaluating the actual process of consensus, it is important to remember that both the Protestant and Catholic representatives who participated in each stage of the legislative discussion were also opposed to the legislation itself*(18,21)*. In other words, while some participants opposed the very existence of a legal framework for end-of-life care, others sought to persuade them to enact the first legislation allowing for the withdrawal of life-sustaining treatment, regardless of its scope. As a result, the point of overlap became the most conservative position among the various opinions, as those advocating for withdrawal of life-sustaining treatment ultimately accepted the most conservative criteria set by those opposed to having any legal framework for end-of-life care.

Signs of people heading towards a cliff

Since the enactment of the first laws addressing end-of-life and death, the public debate has slowly deepened. After some initial confusing reports about the law enabling "death with dignity," over time, there has been a growing body of reporting*(23-28)*, popular books*(29-31)*, public communication content*(32,33)*, and academic researches*(34-37)* that has focused on the unmet needs at the end of life that the law leaves behind. The consensus has been that the current Life-Sustaining Treatment Decision Act is not sufficient to improve end-of-life care in our society. Individual studies and opinions have their own strengths and point to important issues. However, in a context where death has already been medicalized, it was challenging to cut to the heart of this holistic issue, to identify appropriate responses, and, most importantly, to build societal understanding and consensus around it*(38).* The government, in particular, was unable to play a role in educating the public about its limitations and building consensus for the next steps, preoccupied with implementing the new law. Moreover, the issue has not been elevated to the forefront of the debate, at least not in the eyes of the general public. This is a far cry from the experience in the United States, where sensationalized and misleading language such as "death panels" has pushed the issue of end-of-life care and costs up the political agenda*(9,40).* Although the limitations of the current law were discussed, there was little analysis on where those limitations came from. While it was fortunate that the debate did not get heated, it did not get a chance to revisit in the public eye whether the arguments made during the last legislative discussion, including concerns about the "slippery slope," were valid.

Without any subsequent groundbreaking case law or intense politicized debate, a fairly radical change was proposed in an amendment bill in 2022*(4)*. The amendment, which introduced the concept of "assisted death with dignity," was proposed to amend the existing Life-Sustaining Treatment Decision Act*(1)* and was dubbed the "Assisted Death with Dignity" Bill by its proponents. The essence of this bill is to legalize physician-assisted dying by allowing it under the condition that it has received approval from a government committee. The proposal was based on a survey of 1,000 citizens that showed a 76.4% favorable opinion of euthanasia or physician-assisted suicide (EAS)*(41)*. This was interpreted as a significant increase compared to a similar survey conducted by the same corresponding author in 2016, which showed only 41.4% in favor of active euthanasia and 35.9% in favor of physician-assisted suicide*(42)*.

The bill faced stiff opposition from the Ministry of Health and Welfare, various medical professional organizations including the Korean Medical Association, and related societies and organizations such as the Korean Society for Hospice & Palliative Care and the Korean Society for Medical Ethics*(43)*. The bill was automatically discarded due to the expiration of the parliamentary session. However, it would be naïve to consider this legislative attempt as a mere isolated incident and to assume that future attempts of this nature can be consistently prevented. Representative Ahn Kyu-baek, who had previously introduced the amendment, successfully retained his seat in the next parliamentary session and has now proposed a new piece of legislation aimed at addressing physician-assisted dying through a completely new law, not merely as an amendment*(44)*. Moreover, by the end of 2023, a lawsuit was filed arguing that the failure to enact specific legislation permitting physician-assisted dying and the existing laws criminalizing aiding and abetting suicide were unconstitutional*(45)*.

Except for a few fortunate individuals, the majority of patients do not receive adequate care at the end of life. While much attention has been given to hospice utilization, which primarily serves cancer patients, and the insufficient resources available for hospice care*(46)*, a more fundamental issue remains unresolved: whether patient-defined goals of care can be prioritized over aggressive treatments. This issue stems from the Korean legal system's lack of explicit recognition of the right to refuse treatment based on self-determination. This lack of recognition originated from excessive concerns about self-determination and the potential for a slippery slope, which dominated past legislative discussions. Paradoxically, by closing off the more moderate option of treatment refusal, which would have benefited a larger number of people had such a law been in place, attention has shifted to the more radical option of physician-assisted dying, which affects a smaller percentage of patients*(47)*.

Conclusion

The legislative discussion surrounding the enactment of Korea's Life-Sustaining Treatment Decision Act was marked by excessive concerns, and the barricade erected by those expressing these concerns to prevent a "slippery slope" has created significant unmet needs in end-of-life care in Korea, leading to paradoxical outcomes. A topic that had lacked sufficient public discourse was then shaped by the assertions of a specific group of representatives, and even within that process, there was a failure to provide a forum for broad societal learning, participation, and discussion. The radical movement advocating for physician-assisted dying will persist unless it becomes possible to establish treatment goals that are tailored to the patient's medical condition and values, supported by the guarantee of the right to refuse treatment. Now, nearly 15 years after the legislative discussion, it is crucial to assess whether Korean society is prepared to establish legal frameworks that protect the "dignity and value of human beings*(1)*" at the end of life through a more robust social deliberation process. Without increased social engagement aimed at improving the structure of past legislative discussions, it will be impossible to move toward better alternatives. There is a need for democratic deliberation—a structure that effectively communicates specialized content to the public, facilitates their reflection, enables them to express their views and engage in discussion, and ultimately reaches a consensus. Korean society must not ignore the urgent concerns of citizens heading toward a cliff but instead increase its investment in public discourse.

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Conflict of Interest

The author declares no conflict of interest.

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HUMANISING END-OF-LIFE CARE IN CHINA: ETHICAL REFLECTIONS ON THE BARRIERS TO HOSPICE DEVELOPMENT

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Abstract: Hospice care represents the 'last mile' of a person-centred health system, mitigating physical suffering while addressing existential, psychosocial and spiritual needs at life's end. China has recently incorporated hospice services into national health strategies; yet provision remains uneven and, in many regions, embryonic. Drawing on an ethical-humanistic framework that integrates principlism with insights from Confucian care ethics, this review examines the principal barriers to a truly humanised hospice system. We synthesise policy documents and empirical literature to map four interlocking impediments: (i) the marginalization of hospice care in national health priorities; (ii) economic constraints in hospice care access; (iii) lack of scientific understanding of death and hospice care in society; and (iv) inadequate investment in hospice infrastructure and education. Ethical analysis reveals that these barriers compromise the core values of autonomy, beneficence and justice, and undermine the Confucian ideal of yang-sheng shan-zhong (caring for life and dying well). To advance a humanistic hospice model with Chinese characteristics, we propose: (1) optimizing top-level design and government-led mechanisms; (2) increasing financial input and reforming medical insurance policy; (3) optimizing hospice care through education and cultural integration; and (4) accelerating supply-side reform in hospice care. Addressing these ethical and structural deficits is essential to honouring patient dignity and realising equitable, high-quality end-of-life care across China.

Keywords: hospice Care, end-of-life ethics, humanistic care, development barriers, China

Humanización de los cuidados paliativos en China: Reflexiones éticas sobre las barreras para el desarrollo de los hospicios

Resumen: Los cuidados paliativos representan el último escalón de un sistema de salud centrado en la persona, mitigando el sufrimiento físico a la vez que se atienden las necesidades existenciales, psicosociales y espirituales al final de la vida. China ha incorporado recientemente los servicios de cuidados paliativos a las estrategias nacionales de salud; sin embargo, la prestación de estos servicios sigue siendo desigual y, en muchas regiones, incipiente. Basándose en un marco ético-humanista que integra el principialismo con perspectivas de la ética confuciana del cuidado, esta revisión examina las principales barreras para un sistema de cuidados paliativos verdaderamente humanizado. Sintetizamos documentos de políticas y literatura empírica para mapear cuatro impedimentos interrelacionados: (i) la marginación de los cuidados paliativos en las prioridades nacionales de salud; (ii) las limitaciones económicas en el acceso a los cuidados paliativos; (iii) la falta de comprensión científica de la muerte y los cuidados paliativos en la sociedad; y (iv) la inversión insuficiente en infraestructura y educación en cuidados paliativos. El análisis ético revela que estas barreras comprometen los valores fundamentales de autonomía, beneficencia y justicia, y socavan el ideal confuciano de yang-sheng shan-zhong (cuidar la vida y morir bien). Para impulsar un modelo humanista de cuidados paliativos con características chinas proponemos: (1) optimizar el diseño de alto nivel y los mecanismos gubernamentales; (2) aumentar la financiación y reformar la póliza de seguro médico; (3) optimizar los cuidados paliativos mediante la educación y la integración cultural, y (4) acelerar la reforma de la oferta en cuidados paliativos. Abordar estas deficiencias éticas y estructurales es esencial para honrar la dignidad del paciente y lograr una atención paliativa equitativa y de alta calidad en toda China.

Palabras clave: cuidados paliativos, ética del final de la vida, atención humanista, barreras al desarrollo, China

Humanizando Cuidados de Fim da Vida na China: Reflexões Éticas sobre as Barreiras para o Desenvolvimento de Hospedarias de Cuidados Paliativos

Resumo: Uma hospedaria de cuidados paliativos representa a 'última milha" de um sistema de saúde centrado na pessoa, mitigando sofrimento físico à medida que aborda necessidades existenciais, psicossociais e espirituais ao fim da vida. A China recentemente incorporou esses serviços nas estratégias de saúde nacionais; no entanto, sua oferta continua desigual e, em muitas regiões, embrionária. Com base numa estrutura ético-humanística que integra principalismo com compreensões da ética de cuidados confucionista, essa revisão examina as principais barreiras para hospedarias de cuidados paliativos verdadeiramente humanizadas. Nós sintetizamos documentos de políticas e literatura empírica para mapear quatro impedimentos interligados: (i) a marginalização de hospedarias de cuidados paliativos dentre as prioridades de saúde nacionais; (ii) restrições econômicas no acesso a hospedarias de cuidados paliativos; (iii) falta de compreensão cientifica da morte e de hospedarias de cuidados

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paliativos na sociedade; e (iv) investimento inadequado na infraestrutura e educação de hospedarias de cuidados paliativos. Análise ética revela que essas barreiras comprometem os valores centrais da autonomia, beneficência e justiça, e debilitam o ideal confucionista de yang-sheng shan-zhong (cuidando da vida e morrendo bem). Para avançar o modelo de hospedarias de cuidados paliativos humanísticos com características chinesas, nós propomos: (1) otimização do projeto de alto nível e dos mecanismos liderados pelo governo; (2) aumentar a contribuição financeira e reformar as políticas de seguro médico; (3) otimização das hospedarias de cuidados paliativos através da educação e da integração cultural; e (4) acelerar a reforma do lado da oferta em hospedarias de cuidados paliativos. Abordar esses deficits éticos e estruturais é essencial para honrar a dignidade dos pacientes, proporcionando cuidados de fim de vida equitativos e de alta qualidade em toda a China.

Palavras-chave: hospedarias de cuidados paliativos, ética de fim da vida, cuidados humanísticos, barreiras ao desenvolvimento, China

Hospice, or palliative, care is a person-centred, multidisciplinary model in which physicians, nurses, psychotherapists, social workers, spiritual counsellors and other professionals collaborate to address the full spectrum of physical, psychological, social and existential distress experienced by people with incurable, life-limiting illness*(1)*. Rather than pursuing curative treatment, hospice aims to maximize comfort, preserve dignity and enrich the quality of the remaining time. Its remit extends to families through bereavement support and counselling, acknowledging the relational nature of suffering. Equal access to such care for those with advanced illness is now widely recognised as an essential element of the right to health*(2)*. In practice, hospice care crystallises medical humanism by affirming the intrinsic worth of each individual and responding to suffering in all its dimensions.

China's rapid advances in healthcare and social-welfare systems have spurred the emergence of hospice programmes in many provinces, and public demand for end-of-life support is steadily increasing. Yet the palliative-care landscape remains nascent. Deep-rooted cultural reticence toward open discussion of death, pronounced urban-rural and wealth disparities, and a limited, unevenly distributed workforce constrain service reach and quality. These contextual factors preclude the wholesale transplantation of Western hospice models. Therefore, a nuanced appraisal of China's existing infrastructure-its gaps and the cultural, economic and organisational forces that sustain them-is therefore imperative. Only through such analysis can a hospice model with Chinese characteristics be shaped, one that aligns with national values, leverages available resources and meets the evolving needs of society.

1. Overview of hospice care development in China

Hospice care first took root in China during the early 1980s. Over the past decade, central authorities have issued a policy directives that prioritise end-of-life services, earmark funding, and encourage local innovation. This top-down commitment has accelerated the expansion and diversification of palliative-care delivery nationwide. Several municipalities have emerged as test-beds for best practice, most notably Shanghai and Changchun--two of the earliest national pilot cities. Their integrated, community-based programmes, multidisciplinary training schemes, and supportive financing mechanisms now serve as influential reference points for other regions seeking to scale up hospice services across China.

1.1 The Development of Hospice Care Service in China

Hospice care remains in a transitional phase within China's health system. Although widely acknowledged in global health as a basic human right, hospice care in China lacks a dedicated legislative framework, and references to it appear only sporadically across a handful of general laws and policy documents. To date, there is no unified national law governing hospice care as an independent and specialized sector. Instead, hospice services are largely embedded within broader domains such as medical care, eldercare, and social welfare policies, resulting in fragmented governance and limited institutional integration.

A major turning point occurred in 2006 with the founding of t*he Chinese Association for Life Care*, which articulated a mission to develop a hospice model with Chinese characteristics. This marked a formal transition into a new phase of institutional recognition and coordination at the national level. However, the groundwork for hospice care had been laid much earlier. In 1987, Dr. Li Wei established the first hospice ward at a cancer hospital in Beijing, which later evolved into Songtang Hospital, China's first facility dedicated to hospice care. The following year, Tianjin Medical College inaugurated the Hospice Care Research Center, formally initiating hospice care as a distinct academic and service field in China. Further institutional momentum came in 1998, when the Li Ka-shing Foundation funded the country's first hospice sanatorium at the First Affiliated Hospital of Shantou University Medical College, targeting impoverished terminal cancer patients with home-based services.

Over time, governmental attention has gradually increased. In 2012, t*he 12th Five-Year Plan for the Development of Health Services* encouraged private sector participation in hospice care development.

This was followed by more concrete directives: The *Law on the Promotion of Basic Medical and Health Care* and the *Guidance on Establishing and Improving the Elderly Health Service System* both identified hospice care as an integral part of China's broader effort to build a full-cycle, coordinated health service network. Notably, the *2017 Regulation on the Administration of Medical Institutions* formally included hospice centers within the official classification of medical institutions. That same year, the National Health Commission selected Beijing, Shanghai, Changchun, and two other cities to pilot integrated hospice service reforms, gradually expanding the program's reach.

The momentum continued into the current decade. *The 14th Five-Year Plan for the Development of National Undertakings* for the *Aged and Elderly Care Services*, along with the *CPC Central Committee and State Council's Opinions* on *Strengthening Elderly Work in the New Era*, reiterated the need to expand hospice care pilots, promote community-and home-based hospice models, and establish an effective, sustainable service mechanism.

Taken together, these milestones demonstrate that while hospice care in China is still in an emergent phase, it has garnered increasing institutional support.

1.2 Local Practice of Hospice Care in China

The pace of hospice care development in China has accelerated significantly in recent years, largely due to the issuance of supportive national policies and the implementation of localized pilot initiatives. Despite these gains, China has yet to establish a unified and standardized national hospice care delivery system. Current service provision remains largely fragmented and depends heavily on pilot cities and regions that adapt their approaches according to local demographic, economic, and institutional conditions. Among them, Shanghai and Changchun, two of the earliest designated pilot cities, offer instructive and representative models of hospice service delivery in the Chinese context.

Shanghai has pioneered a community-based, home-oriented hospice care model that has become a hallmark of its end-of-life care infrastructure. As one of China's most rapidly aging cities, Shanghai began developing hospice services over a decade ago. It remains the only provincial-level city to implement hospice care pilot programs comprehensively across all districts. In 2012, Shanghai launched the *'Hospice Care Government Practical Project'*, and in 2017, hospice care was formally incorporated into the Healthy Shanghai 2030 Plan. Over the subsequent years, various municipal departments issued guiding documents such as the *Shanghai Hospice Pilot Implementation Plan* and the *Shanghai Hospice Service Specification*. According to information released during the *2023 World Hospice and Palliative Care Day* events in Shanghai, all community health service centers in the city now provide hospice care, creating a broad and accessible community-led network for end-of-life support*(3)*.

Changchun, another early pilot city, has taken a distinctive path by embedding hospice care within the medical insurance system. As early as 2014, the city's Human Resources and Social Security Bureau launched pilot projects to offer full-process hospice services--encompassing daily care, symptom management, and psychological counseling--to terminally ill patients covered by insurance. In 2017, Changchun reformed its reimbursement structure by introducing single-disease fixed payments, making it the first city in China where hospice services received independent support from the medical insurance system*(4)*. Further institutional progress was marked on December 27, 2023, with the establishment of the Changchun Hospice Quality Control Center. This body issued the first set of local quality control standards, covering domains such as nurse training, pharmaceutical management, and facility design. This development signals a new stage in the professionalization and standardization of hospice services in Changchun.

These two models—Shanghai's community-led, service-integrated approach and Changchun's insurance-driven, institutionalized pathway—together illustrate the range of strategies currently shaping hospice development in China. Their experiences offer valuable policy and implementation insights for other regions aiming to advance equitable and culturally responsive end-of-life care.

2. The Development Dilemma of Hospice Care Service in China

In recent years, China has made notable strides in promoting hospice care, supported by increasing governmental attention, policy initiatives, and pilot program expansion. The overall development trajectory is encouraging. Nevertheless, the hospice care system remains in a nascent stage, having emerged relatively late compared to many high-income countries. Its growth has been shaped—and in many ways constrained—by a complex interplay of cultural, economic, institutional, and systemic factors. These persistent challenges continue to hinder the equitable, scalable, and sustainable delivery of hospice services across the country.

Key obstacles include the influence of traditional cultural attitudes, particularly the widespread taboo surrounding death and dying, which limits public acceptance and open discussion of end-of-life care. Meanwhile, policy fragmentation and the lack of a dedicated legislative framework weaken coordination across healthcare, social services, and insurance systems. The shortage of trained hospice professionals and gaps in interprofessional education and public awareness, further restrict service capacity and quality. Addressing these interwoven dilemmas requires structural reform and policy innovation but also a culturally grounded redefinition of hospice values that integrates indigenous ethical traditions. Only by tackling these multifaceted barriers can China develop a hospice care system that is responsive, inclusive, and rooted in the lived realities of its aging population.

2.1 Insufficient Policy Support

Policy support plays a pivotal role in shaping the development trajectory of hospice care, as evidenced by both national initiatives and local pilot programs in China. A well-structured hospice care system not only reflects the level of social welfare in a country but also contributes to social stability by addressing the needs of aging and terminally ill populations. However, in China, hospice care is still predominantly perceived as a medical issue, rather than a broader social and public health concern. This narrow framing limits its integration into the national health and social service infrastructure. Although the government has issued a series of policies in recent years aimed at encouraging the development of hospice care, these measures remain largely advisory in nature-focused on advocacy and moral encouragement rather than enforceable mandates. Critically, China has yet to enact dedicated legislation governing hospice care. Most existing policies fall under the category of ‘soft law,’ offering general guidance without clear accountability, implementation mechanisms, or legally binding standards.

Furthermore, key components required for systemic development--such as sustainable financial investment, regulatory frameworks, and infrastructure planning--are inadequately addressed. The current policy environment lacks clarity regarding essential operational details: What are the formal entry and accreditation standards for hospice institutions? How should essential medications, specialist equipment, and staffing resources be sourced, financed, and regulated? Who holds responsibility for ensuring quality control and long-term service continuity? This regulatory ambiguity results in fragmented service delivery and inhibits large-scale, coordinated development. Without robust legal and financial foundations, hospice care in China remains largely experimental and localized, unable to achieve the comprehensive, equitable, and institutionalized presence seen in more mature systems. Bridging this policy gap is a fundamental step toward scaling and systematizing hospice care nationally.

2.2 Economic Constraints

The high cost of care for terminally ill patients is a universal challenge, and China is no exception. Despite achieving a ‘complete victory’ in the national campaign against poverty, significant regional and household-level economic disparities persist. In particular, low-income families in underdeveloped areas remain vulnerable to financial distress in the face of prolonged illness. For many, the cost of aggressive treatments during the late stages of illness can quickly exhaust household savings, leading families to forgo further treatment or withdraw prematurely due to unaffordable expenses. Within this context, hospice care—despite being a cost-effective and humane alternative to futile curative interventions—remains financially out of reach for many families. Although China's medical insurance system provides partial reimbursement for some terminal care expenses, the overall coverage remains insufficient. Terminal patients requiring long-term hospitalization often exceed the average reimbursement threshold, placing pressure on hospitals to limit their length of stay or discharge them entirely. As a result, patients in relatively stable but deteriorating conditions are frequently persuaded to transfer, denied admission, or repeatedly turned away, eventually leading to an involuntary exit from institutional care.

Moreover, the financial strain extends to hospice institutions themselves. Due to limited government subsidies and an underdeveloped financing model, many facilities struggle to remain economically viable. The combination of high operational costs, low profit margins, and insufficient insurance reimbursement mechanisms has led to closures or reductions in service capacity. Without structural reforms to funding and insurance policies, the economic barriers facing both patients and providers will continue to hinder the expansion and sustainability of hospice care in China. To ensure equitable access and institutional stability, it is essential to develop a multi-channel financing system that includes public funding, insurance support, and social donations, along with clear reimbursement guidelines tailored to the unique cost structure of hospice services.

2.3 Cultural and Conceptual Barriers

The development of hospice care in China represents not only a medical and policy innovation but also a profound cultural challenge to traditional understandings of life and death. As a model of care that emphasizes dignity, comfort, and acceptance of death, hospice care often runs counter to longstanding cultural norms that view death as a taboo subject to be avoided rather than openly discussed. While public awareness and acceptance of hospice care have grown in recent years, deep-rooted cultural resistance continues to constrain its broader integration into mainstream healthcare.

One of the most significant cultural barriers stems from traditional Confucian notions of filial piety, which emphasize doing everything possible to prolong the lives of one's parents. In practice, this often translates into the pursuit of aggressive, sometimes futile, medical interventions at the end of life. Families may experience moral conflict or social pressure when considering hospice care, fearing judgment from relatives or society that such a choice constitutes abandonment or a lack of filial devotion. This internalized tension makes it difficult for families to reach consensus or make timely decisions about palliative options. Additionally, religious and spiritual beliefs can influence end-of-life decisions. For instance, in some faith traditions, life is regarded as sacred and divinely ordained, with only a higher power holding the authority to determine its end. As noted by Trotzuk and Gray*(5)*, such beliefs may lead to the rejection of hospice care if it is perceived as passive or indicative of 'giving up.'

Another major barrier is the lack of death education in Chinese schools and public discourse. Despite significant advancements in general education, curricula on death, dying, and hospice philosophy remain scarce. While safety topics like fire drills and drowning prevention are commonly taught, death remains largely absent from both formal education and societal dialogue. As a result, many individuals enter adulthood with limited understanding of hospice care and a generalized fear or anxiety about death. This leads to widespread misconceptions—such as equating hospice care with 'waiting to die'—and perpetuates a preference for aggressive, often excessive, medical interventions until the final moments of life.

These misunderstandings also contribute to communication breakdowns between medical teams and families. Physicians may encounter reluctance or hostility when initiating end-of-life conversations, and families may resist hospice referrals, fearing they represent medical abandonment. In some cases, this cultural disconnect can even escalate into conflict, further undermining trust and impeding the timely provision of compassionate care.

Overcoming these barriers requires a multi-faceted cultural shift--one that includes integrating death education into school curricula, normalizing end-of-life discussions in public discourse, and reframing hospice care not as surrender, but as a form of active, humane support aligned with the values of dignity and relational responsibility.

2.4 Insufficient service supply

As China experiences accelerated population aging, the demand for hospice care services is rising sharply. However, the current capacity of the system remains significantly inadequate to meet this growing societal need. The mismatch between demand and supply manifests in three interrelated dimensions: infrastructure deficits, workforce shortages, and a narrow service structure.

First, there is a notable lack of infrastructure and material resources. Many regions—particularly less-developed or rural areas—either lack hospice facilities altogether or are only in the early stages of development. Even in urban areas, the number of dedicated hospice hospitals, palliative care wards, beds, and specialized equipment remains far below demand. In many general hospitals, hospice services are not available, or are confined to a few under-resourced wards. This limits access and constrains continuity of care for terminal patients.

Second, the shortage of qualified professionals further hampers service delivery. Hospice care is inherently interdisciplinary, requiring the collaborative efforts of physicians, nurses, psychotherapists, social workers, and spiritual care providers. These professionals must not only possess clinical expertise but also be trained in communication, emotional support, bereavement care, and ethical decision-making. Yet, China faces a significant shortage of such personnel, and many current practitioners lack access to systematic, specialized training. This gap in human resources leads to variations in care quality and further discourages the expansion of services.

Third, China's hospice service model remains overly dependent on hospital-based care, with limited development of community and home-based hospice services, which are often more accessible and cost-effective. While hospitals can offer high-level medical care, hospice is not a prioritized department within most institutions, especially those under resource constraints. Consequently, existing services are limited in scope and availability, and the potential of community health centers and home-based models—central components in mature hospice systems globally—remains underdeveloped.

To address these structural weaknesses, China must invest in a multi-level hospice care delivery system. Only through coordinated investment and systemic reform can China ensure the scale, quality, and sustainability of hospice care services necessary to meet the needs of its aging population.

3. Underlying Causes of the Development Dilemma in Hospice Care in China

Hospice care plays a critical role in optimizing the healthcare system by addressing the needs of terminally ill patients through compassionate, cost-effective, and patient-centered services. However, despite growing policy attention and pilot programs, the development of hospice care in China remains constrained by multiple structural and systemic barriers, including insufficient policy support, economic disparities, cultural resistance, and limited service capacity.

To move beyond these entrenched challenges and chart a scientific, evidence-based path forward, it is essential to conduct a comprehensive and multi-dimensional analysis of the underlying causes behind the current developmental impasse. This requires not only identifying what the obstacles are, but also exploring why they persist--how policy, financing, culture, education, infrastructure, and workforce systems interact to produce inertia or fragmentation in service delivery. Moreover, the formulation of a sustainable and effective national hospice strategy hinges on addressing two core questions:

(i) What needs to be done to build a hospice care system that is equitable, culturally appropriate, and institutionally integrated?

(ii) How can it be done in a way that aligns with China's social realities, healthcare reforms, demographic trends, and traditional values?

The answers to these questions must guide the development of targeted interventions from legislative reform and multi-source financing, to death education, workforce development, and the expansion of community and home-based care models. Only through such a strategic and context-sensitive approach can China break through the current development bottlenecks and advance toward a hospice care system that truly reflects humanistic values and public health priorities.

3.1 The Marginalization of Hospice Care in National Health Priorities

The World Health Organization (WHO) has long advocated for healthcare systems that are accessible, acceptable, high-quality, and cost-effective, emphasizing the importance of nursing and palliative services in achieving universal health coverage and advancing the Sustainable Development Goals (SDGs)*(2)*. As a crucial component of these global health objectives, hospice care not only alleviates physical and psychological suffering but also upholds the dignity of terminally ill patients through comprehensive, multidisciplinary support. Ethically grounded and cost-efficient, hospice care should be recognized as an integral pillar of public health infrastructure.

However, in China, the importance of hospice care has not been sufficiently embedded within the national health strategy. Despite commendable progress in pilot programs, the service remains policy-marginalized and structurally underdeveloped. The formulation of health policies in China continues to align primarily with public expectations that prioritize life extension and disease prevention, rather than quality of life at the end of life*(6)*. Within this policy landscape, hospice care is often seen as secondary or optional, rather than essential.

One of the most significant institutional limitations is the absence of a comprehensive legal framework specifically governing hospice care. Existing regulations are fragmented and lack the enforceable provisions and funding mechanisms necessary for systematic development. Consequently, hospice care continues to be guided by soft policy instruments, non-binding guidelines, and pilot directives that encourage experimentation without providing sufficient financial or infrastructural backing.

This structural weakness is further compounded by the foreign origin and late introduction of hospice care in China, which has limited its cultural resonance and slowed its integration into domestic policy frameworks. While many cities have achieved notable progress in recent years through localized experimentation, the accumulated body of replicable, context-specific experience remains insufficient. This poses a challenge for national-level policymakers who must navigate between universal principles such as palliative rights and patient autonomy, and contextual particularities such as filial obligations*(7)* and rural-urban disparities*(8)*. As a result, current policies lack the grounded evidence base necessary to ensure their effectiveness across diverse settings.

Ultimately, the failure to position hospice care as a core element of China's health undertaking has led to weak policy enforcement, insufficient funding allocation, and minimal strategic integration. Reversing this trend requires not only a shift in public health priorities, but also a reframing of hospice care as a humanistic, ethical, and systemic necessity, rather than a peripheral or charitable service.

3.2 Economic Constraints in Hospice Care Access

Alleviating the physical, emotional, and financial burdens associated with life-limiting illnesses is not only a humanitarian obligation but also a foundational element of a fair and inclusive health system. Yet in China, significant economic disparities, a still-maturing medical insurance infrastructure, and an uneven distribution of personal income continue to hinder the widespread and equitable development of hospice care services. Compared to high-income countries, China's economic capacity to fund comprehensive end-of-life care remains limited. The current basic medical insurance system, while expansive in its population coverage, is still primarily designed to support curative treatment and disease prevention--leaving end-of-life care underprioritized and underfunded. As a result, hospice services are often accessible only to higher-income groups, while economically disadvantaged populations, who equally suffer intense physical and psychological distress, are often excluded from care due to cost.

This inequity directly contradicts the traditional Chinese cultural ideal of a ‘good death’, which includes not only dying peacefully, but also doing so with minimal pain and psychological suffering. For many low-income families, however, such ideals are financially out of reach. The cumulative costs of prolonged hospital care, coupled with the limited reimbursement available for hospice services, force some families to abandon treatment altogether--not out of choice, but out of necessity. In extreme cases, this economic burden can lead to psychological breakdowns, intrafamilial conflict, or delayed or denied care, further compromising patients’ dignity and social stability.

In response to similar challenges, some high-income countries have adopted all-inclusive medical security models that guarantee access to hospice and palliative care. However, China’s development stage, population scale, and fiscal constraints make such a model unrealistic in the near term. With limited public funds and competing demands for investments in areas such as primary care, chronic disease management, and health infrastructure, end-of-life care continues to receive minimal financial prioritization. This situation is further compounded by policy-making logics that emphasize health investments that yield high returns in productivity and longevity--often at the expense of those at the end of life, whose care needs are deemed less economically justifiable*(2)*. As a result, government funding allocations rarely extend to terminally ill patients, perpetuating the cycle of underdevelopment in hospice services and reinforcing health inequities between rich and poor.

To address these challenges, China must adopt a tiered, context-sensitive financing strategy. While universal, all-inclusive hospice coverage may not be immediately feasible, incremental measures—such as targeted hospice subsidies for low-income families, expanded insurance reimbursement pilots, and increased support for community-based models—can significantly expand access while remaining fiscally responsible. Additionally, public financing priorities should be reframed to recognize that supporting a humane death is not a luxury, but a social right, integral to both individual dignity and collective social stability.

3.3 Lack of Scientific Understanding of Death and Hospice Care in Society

Public perception and cultural attitudes toward death play a critical role in shaping the acceptance, timing, and effectiveness of hospice care. In the context of China, the absence of a scientifically grounded and socially normalized understanding of death remains a major obstacle to the widespread adoption of hospice services.

First, deeply rooted traditional beliefs and cultural taboos contribute to widespread death avoidance. Death is often viewed as inauspicious and is seldom discussed openly, especially in family or medical contexts. Influenced by Confucian values and religious beliefs, many continue to regard life as sacred and divinely controlled, believing that only higher powers have the authority to determine life and death*(5)*. These beliefs discourage proactive conversations about dying and contribute to societal discomfort with end-of-life planning.

Second, hospice care is frequently misunderstood as equivalent to “giving up” on life or withdrawing active treatment. Many patients and their families interpret the initiation of hospice as a form of abandonment or surrender, rather than as a shift in focus from cure to comfort. As a result, discussions about hospice are often delayed until all curative options have been exhausted, by which time the optimal therapeutic window for initiating palliative interventions has already closed.

Third, patients’ and families’ understanding of death often fluctuates depending on the stage of illness. During critical phases, the reality of death may temporarily prompt reflection and acceptance. However, once the patient stabilizes, there is a common tendency to confuse stabilization with recovery, fostering false hope and renewed insistence on curative treatment. This cyclical denial complicates efforts to establish timely care plans that include palliative options*(5)*.

In essence, China—like many other countries—operates within a death-denying social framework, where discussions of mortality are routinely postponed or avoided altogether. This creates a situation in which hospice care is often initiated too late—only when death is imminent and families are forced to confront reality. At this point, the patient's condition may be so advanced that the benefits of hospice care (pain management, psychological support, dignity preservation) can no longer be fully realized. As Greenstein, Policzer, and Shaban*(9)* note, such delayed referrals reinforce a false narrative that 'hospice is where patients go to die,' further entrenching public mistrust and misunderstanding.

Addressing this cognitive gap requires systemic investment in death education and public awareness campaigns, integrated into schools, community programs, and healthcare settings. Normalizing conversations about end-of-life care and reframing hospice as an active, compassionate, and empowering choice—rather than a passive acceptance of death—is essential to building a society that embraces death as a natural phase of life. Only through this cultural shift can hospice care be accessed earlier, accepted more widely, and practiced more effectively.

3.4 Inadequate Investment in Hospice Infrastructure and Education

The level of resource investment—both material and human—is a key determinant of the scope and quality of hospice care services. In China, the development of hospice care remains constrained by insufficient funding, structural imbalance in service delivery, and underinvestment in workforce education and training.

From a financial perspective, the allocation of healthcare resources remains disproportionately focused on life-prolonging interventions and productivity-oriented outcomes, such as disease prevention and curative treatment. As discussed earlier, public misunderstanding of hospice care and policy emphasis on 'living longer' rather than 'dying well' have led to chronically low levels of government investment in hospice infrastructure. This underfunding has produced widespread shortages of essential medications, medical equipment, beds, and hospice ward coverage. Many hospitals lack dedicated hospice units altogether, and those that do exist are often under-resourced and unable to meet growing demand.

Additionally, the service delivery structure remains overly centralized, with hospice care largely concentrated in tertiary hospitals. Community, and home-based hospice models—which are critical for increasing accessibility and reducing the burden on hospitals—remain underdeveloped. As a result, patients must often seek hospice care in hospitals regardless of the severity of their condition or their personal preference for home-based end-of-life care. Yet hospice is typically not a priority department within hospital systems, leading to limited ward allocation, low staff capacity, and suboptimal service delivery, particularly during periods of acute demand.

Beyond physical infrastructure, the shortage of trained, multidisciplinary personnel significantly weakens hospice service capacity. Hospice care requires holistic, team-based coordination to address the multifaceted needs of terminally ill patients and their families. Physicians and nurses focus on managing physical symptoms, while psychotherapists, social workers, and caregivers provide psychological, emotional, and practical support. However, this ideal team structure is difficult to implement in practice due to the limited availability of trained professionals and the low visibility of hospice as a legitimate medical career pathway. A core reason for this workforce shortfall is the insufficient integration of hospice care education into China's formal education system. Although some medical students are introduced to the basic principles of palliative care, few universities offer specialized courses or degree programs in hospice care. Non-medical students—such as those in social work, psychology, or community health—rarely encounter end-of-life care content in their curricula*(10)*. This results in a limited talent pipeline and a lack of interdisciplinary coordination essential for effective hospice care.

Furthermore, due to public misperceptions and persistent cultural taboos surrounding death, few healthcare workers are willing to specialize in hospice care. The emotional demands of caring for dying patients, combined with the low social recognition of this profession, discourage long-term engagement. In many settings, hospice services rely heavily on untrained volunteers, whose participation is often irregular and unsustainable. While volunteerism can complement formal care, reliance on it without professional support undermines the consistency, quality, and scalability of hospice programs.

To address these interrelated deficits, China must increase fiscal investment in hospice care infrastructure, diversify service settings beyond hospitals, and integrate hospice education into professional training pipelines across multiple disciplines. Strengthening both material and human resource foundations is essential to building a resilient, equitable, and high-quality hospice care system aligned with the country's demographic and ethical imperatives.

4. The Development Path of China´s Hospice Care Service

Although hospice care does not aim to prolong life, it plays a vital role in relieving the physical, psychological, and existential suffering of terminally ill patients, thereby preserving dignity and enhancing the quality of life in the final stage. As such, it should be regarded as an essential component of a comprehensive and humane healthcare system. However, the development of hospice care in China remains incomplete and uneven, constrained by institutional, financial, cultural, and educational barriers.

To overcome these multifaceted challenges, a multi-dimensional and coordinated development strategy is urgently needed. Rather than relying on isolated pilot initiatives or temporary policy incentives, the country must work toward establishing a systematic, scalable, and sustainable hospice care service model that integrates policy reform, economic support, cultural transformation, and professional capacity-building. Ultimately, the path forward for hospice care in China lies in balancing international standards with local values, drawing on successful global models while tailoring implementation to China's unique demographic, cultural, and institutional context. By advancing hospice care as both a human right and a public health imperative, China can build a more compassionate, inclusive, and ethically grounded healthcare system for its aging population.

4.1 Insufficient Policy Support: Optimizing Top-Level Design and Government-Led Mechanisms

As a vital component of China's evolving healthcare and elderly care systems, hospice care aligns with national development goals and public expectations, helping to address pressing social issues related to aging, end-of-life care, and equitable access to services. It also reflects the Party and government's commitment to improving the well-being and dignity of citizens, particularly the most vulnerable*(11)*. Given hospice care's public welfare nature, its structure, accessibility, and sustainability are heavily dependent on governmental planning, regulation, and investment.

To accelerate the development of hospice care in China, it is essential to elevate it to a strategic priority within national healthcare and social service systems, and to optimize its top-level design through comprehensive, government-led mechanisms. Several strategic reforms are needed to build a solid institutional foundation for large-scale, equitable hospice service delivery:

First, there is an urgent need to establish a comprehensive and independent legal and regulatory framework for hospice care. This framework should clearly define the rights and obligations of stakeholders, including service providers, patients, families, and regulatory bodies. It must also delineate essential operational elements—such as the provisioning of medications, equipment, personnel, and facilities—to ensure consistent quality and resource availability. Assigning responsibility to designated agencies for the management and distribution of these resources would enhance implementation and accountability.

Second, policymakers should explore the creation of an independent hospice care department within the National Health Commission. This specialized unit would serve to institutionalize the strategic importance of hospice care, enhance administrative efficiency, and facilitate effective oversight of local implementation. It would also act as a coordination hub, strengthening interdepartmental collaboration across sectors such as healthcare, civil affairs, social security, and education.

Third, the government should expand and diversify hospice care pilot programs across a wider range of regions, with particular emphasis on urban-rural comparability. By documenting and analyzing localized experiences, successes, and challenges, the state can build an evidence-based foundation for future national expansion. Lessons drawn from Shanghai, Changchun, and other pioneers should be synthesized to guide scalable models of care tailored to regional needs.

Finally, while private-sector participation can complement service provision, the government must retain a leading role in ensuring equity and consistency. Excessive marketization—particularly in the absence of strong public oversight—risks generating service disparities and undermining public trust. Through macro-level regulation, resource reallocation, and policy harmonization, the state can promote the healthy development of the hospice care market and mitigate the inequalities caused by geographic, economic, and institutional variations.

In sum, the future of hospice care in China depends on a strong, integrated, and responsive governance framework. This requires not only legal and administrative reforms but also visionary leadership and cross-sectoral coordination--anchored in the principle that dying with dignity is a public good and a moral imperative within a just and humane society.

4.2 Economic Limitations: Increasing Financial Input and Reforming Medical Insurance Policy

The sustainable development of hospice care requires not only supportive policies but also robust and stable financial investment. Hospice care typically targets patients with a prognosis of six months or less and encompasses not only symptom management but also care for comorbid conditions, psychological support, and family counseling. Given the complexity and long-term nature of care, hospice services must be embedded within a comprehensive financing system that alleviates the economic burden on patients, families, and providers.

Currently, the financing of hospice care in China is primarily reliant on government subsidies and out-of-pocket expenditures by patients and their families. However, after prolonged curative treatments, many terminally ill patients are financially depleted, and their families often face economic hardship or even poverty due to high medical expenses. This financial strain is exacerbated by the lack of standardized charging mechanisms and inconsistent reimbursement practices across regions.

To address this, policymakers should draw on successful local pilot experiences and integrate hospice care into the national medical insurance system. This would involve: (i) Establishing uniform service pricing standards; (ii) Standardizing reimbursement policies; and (iii) Expanding insurance coverage to include both hospice diagnoses and associated care needs.

These steps would help reduce not only the financial burden but also the psychological distress of patients and caregivers. In tandem, targeted social support programs should be introduced to prevent families from sacrificing basic living needs to care for terminally ill loved ones.

Importantly, China should not attempt to replicate the all-inclusive models used in some high-income countries, but instead tailor reforms to fit its own socioeconomic and institutional realities. For example, local governments with stronger fiscal capacity could allocate designated hospice care funds within the insurance system. Alternatively, a tiered reimbursement structure could be developed, differentiating between patients with long-term hospice needs and those requiring intermittent or short-term care, and adjusting the support levels according to service setting (hospital, community, or home).

Nonetheless, incorporating hospice care into insurance coverage brings its challenges. As coverage expands, the share of insurance expenditures dedicated to hospice services will rise, potentially reducing the operating margins of hospice institutions. Without adequate compensation, this may discourage provider participation or lead to the closure of financially vulnerable facilities.

To mitigate these risks, the government should implement supplementary fiscal measures, such as: (i) increasing direct investment in hospice infrastructure and service capacity; (ii) offering tax incentives or exemptions to hospice institutions; and (iii) subsidizing operational costs for non-profit or community-based hospice providers.

By simultaneously reforming the insurance system and providing financial safeguards for service providers, China can build a more equitable, accessible, and financially sustainable hospice care system that protects both patients and the institutions that serve them.

4.3 Cultural Concept Differences: Optimizing Hospice Care Through Education and Cultural Integration

Hospice care represents a paradigm shift in how societies approach death and dying--moving from a focus on life extension at all costs to a holistic concern for quality of life in the final stage of illness. However, in China, this shift faces cultural and psychological resistance, deeply rooted in traditional views of life and death, and in Confucian ideals of filial piety. Under such influences, death is widely perceived as a taboo subject, and conversations surrounding it are often avoided. Within this atmosphere of fear, denial, and moral ambivalence, hospice care remains misunderstood and marginalized.

To change this, it is imperative to advance public life education and promote a culturally resonant understanding of ‘a good death’. However, this process must be gradual and context-sensitive. Rather than directly opposing traditional values, hospice education should aim to integrate the positive elements of Chinese cultural heritage--such as reverence for elders, family unity, and compassion--into modern palliative care principles. Through a dialectical approach, traditional beliefs can be reinterpreted to support rather than hinder hospice care awareness.

Practical strategies for popularizing hospice knowledge include: (i) hosting community-based educational lectures and workshops to foster open dialogue about death, dying, and end-of-life care; (ii) leveraging new media platforms such as WeChat, Weibo, RED (Xiaohongshu), and Bilibili to disseminate accessible and engaging content about hospice care; (iii) embedding hospice-related themes into TV series, films, short videos, and documentaries, which can help destigmatize hospice care by emotionally resonating with broader audiences*(10)*.

Such initiatives can cultivate a more informed, accepting, and ethically supportive environment, ultimately positioning hospice care as a public health priority and a legitimate, even preferable, end-of-life care choice.

Equally important is the need to differentiate hospice care from common misconceptions, particularly from abandonment of treatment or euthanasia. Due to the unpredictable trajectories of many life-limiting illnesses, patients’ prognoses are often uncertain, leading to delays in initiating hospice care due to hesitation from families or physicians. In this context, hospice care should be presented not as a binary alternative to curative treatment, but as part of a dynamic care continuum, where palliative and life-prolonging treatments coexist and gradually shift in emphasis according to the patient’s evolving needs*(12)*.

From a clinical perspective, it is crucial to educate both healthcare providers and the public that hospice care is not synonymous with end-of-life care alone. Rather, it is an integrated, multidisciplinary model aimed at improving the quality of life for patients with serious illness at any stage. This reframing can help alleviate fears that choosing hospice care equates to giving up hope or withdrawing medical attention. Instead, it can be recognized as a form of proactive, compassionate care that affirms dignity and human connection at one of life’s most vulnerable moments.

By transforming public perception through cultural integration, strategic communication, and professional education, China can lay the ethical and social groundwork for the broader acceptance and timely adoption of hospice care services.

4.4 Insufficient Service Supply: Accelerating Supply-Side Reform in Hospice Care

Although hospice care in China has advanced in recent years, its development remains constrained by economic limitations, unbalanced service structures, and a lack of professional capacity. With increasing life expectancy and changing disease patterns, hospice care is no longer an optional or marginal service--it is becoming a structural and ethical necessity in the health system. To meet growing and diversifying demand, it is urgent to pursue comprehensive supply-side reform of hospice care services.

First, China must build a multi-tiered, integrated hospice service delivery model grounded in the collaboration of 'family + community + hospital'. At present, hospice care is largely confined to hospital settings, where wards and facilities remain limited, underfunded, and under-recognized within institutional hierarchies. However, for many terminal patients—especially those with stable symptoms or non-acute needs—home-based and community-based hospice services are more practical, accessible, and aligned with patients' end-of-life preferences.

In this respect, the Shanghai community´s home hospice care model offers a compelling reference. This model should be expanded, adapted, and scaled nationwide to address resource gaps and reduce the over-reliance on hospital-based care. To support this shift, governments should increase financial investment, optimize resource allocation, and expand hospice infrastructure, including the number of dedicated hospice beds, ward space, and essential medical equipment. These improvements would significantly enhance the overall capacity and flexibility of hospice service delivery.

Second, the success of any hospice system depends fundamentally on the strength and quality of its professional workforce. A multidisciplinary hospice care team—comprising doctors, nurses, psychotherapists, social workers, and chaplains—must be equipped to offer not only medical care, but also psychosocial, emotional, and spiritual support to patients and families. However, there is a shortage of qualified personnel in this field, and the existing workforce often lacks systematic training. To address this, several parallel efforts are necessary:

In-service training for clinical staff in departments frequently involved in end-of-life care (e.g., oncology, geriatrics) should be institutionalized. These programs should help healthcare professionals cultivate scientific understanding, positive attitudes, and practical competencies in hospice care through regular continuing education delivered by trained specialists.

Pre-job orientation programs for newly recruited hospice care staff should ensure that caregivers enter the field with a foundational knowledge of palliative principles, ethical considerations, and team-based practices*(10)*.

Establish a system of peer-led reflection and clinical exchange, allowing interdisciplinary teams to share experiences, discuss complex cases, and refine care protocols. Regular debriefings and clinical rounds contribute to collective learning and service improvement*(9)*.

Promote academic research and scholarly dialogue in the hospice care field. This includes not only summarizing domestic pilot experiences but also actively learning from international models and evidence-based practices, adapted to China's sociocultural context.

Finally, strengthen hospice education within the formal higher education system. Universities should integrate hospice-related content as compulsory courses for medical students and elective courses for students in social work, psychology, and other relevant disciplines. This approach will both expand awareness and encourage career interest, fostering a new generation of hospice professionals and researchers*(10)*.

In sum, to meet the anticipated increase in hospice care demand, China must move beyond hospital-centric, resource-limited models toward a diversified, community-rooted, and professionally supported hospice system. This transition requires not only physical infrastructure and financing, but also a deep investment in human capital, service innovation, and sustained policy commitment.

5. Conclusion

With increasing life expectancy and shifting epidemiological patterns, the demand for hospice care services in China is steadily rising. Although the development of hospice care began relatively late, recent years have seen encouraging momentum--reflected in evolving policy support, the expansion of pilot programs, and growing public discourse. These developments have laid a promising foundation for the institutionalization of hospice care across the country.

Nevertheless, major structural and systemic challenges persist. Hospice care has yet to be fully recognized as a core component of China's health system. Key constraints--such as insufficient policy support, economic limitations, cultural misconceptions, underinvestment in infrastructure and education, and imbalanced service supply--continue to hinder its comprehensive development. These issues not only delay the delivery of compassionate, patient-centered end-of-life care but also limit the overall optimization of the nation's medical service system.

Hospice care is not an optional supplement--it is an ethical imperative and an institutional necessity for any health system that aspires to dignity, equity, and quality across the life course. To move beyond the current developmental bottlenecks, China must prioritize reforms in several strategic areas:

(i) Strengthening government-led mechanisms and top-level design to provide legal and financial stability;

(ii) Accelerating supply-side reforms to diversify care models and expand access;

(iii) Innovating the medical insurance system to reduce financial barriers for patients and institutions;

(iv) Promoting national life education to reshape cultural attitudes and normalize hospice care as a humane and proactive choice.

Only through coordinated, multi-sectoral efforts grounded in China's specific national and local realities can the country develop a sustainable, equitable, and culturally responsive hospice care system. Such a model--rooted in both global standards and traditional values--will not only improve end-of-life care for millions but also represent a significant step forward in advancing the moral and humanistic foundation of China's healthcare undertaking.

Author Contributions

The authors confirm being the cooperative contributor of this work and has approved it for publication.

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RESEARCH ON THE EVALUATION INDICATOR SYSTEM OF TEACHING QUALITY FOR GRADUATE STUDENTS IN HEALTH MANAGEMENT

Hongda Gao[1], Tingting Xu[2], Nan Jiang[3], He Chen[4]

Abstract: This study aimed to develop a comprehensive evaluation indicator system for assessing the teaching quality (TQ) of graduate students majoring in Health Management. The evaluation indicator system was built using the Delphi Method with 20 senior experts who have extensive experience in health management education and research. The final evaluation system was applied in a case study at Guangxi Medical University. The weight of Teaching Staff (0.381) and Teaching Target (0.381) is higher than that of the Teaching Process (0.237). In the Teaching Staff dimension, experts emphasize that Professional Qualities (0.057) play a key role in TQ, especially Teaching Reflection (0.255) and Political Literacy (0.255). In the Teaching Target dimension, Student Research Output (0.072) and Assessment Criteria (0.065) are the core factors. In the Teaching Process dimension, the weight of Teaching Methods (0.565) is higher than that of Teaching Content (0.435). For the Teaching Staff, experts and students agree that the weight of Professional Expertise is the lowest. In summary, the Professional Qualities in Teaching Staff dimension, especially Teaching Reflection and Political Literacy, are the key factors affecting TQ. Student Research Output and Assessment Criteria are the core factors in the evaluation of Teaching Target.

Keywords: evaluation indicator system, teaching quality, graduate students, health management, delphi

Investigación sobre el sistema de indicadores de evaluación de la calidad de la enseñanza para estudiantes de posgrado en gestión de la salud

Resumen: El objetivo de este estudio fue desarrollar un sistema integral de indicadores de evaluación para medir la calidad de la enseñanza (CE) de los estudiantes de posgrado en el área de Gestión de la Salud. El sistema de indicadores de evaluación se construyó utilizando el Método Delphi con la participación de 20 expertos senior con amplia experiencia en la educación e investigación en gestión de la salud. El sistema de evaluación final se aplicó en un estudio de caso en la Universidad Médica de Guangxi. El peso del Personal Docente (0,381) y del Objetivo de Enseñanza (0,381) fue mayor que el del Proceso de Enseñanza (0,237). En la dimensión del Personal Docente, los expertos destacaron que las Cualidades Profesionales (0,057) desempeñan un papel clave en la CE, especialmente la Reflexión sobre la Enseñanza (0,255) y la Alfabetización Política (0,255). En la dimensión del Objetivo de Enseñanza, la Producción Académica de los Estudiantes (0,072) y los Criterios de Evaluación (0,065) se consideran los factores clave. En la dimensión del Proceso de Enseñanza, el peso de los Métodos de Enseñanza (0,565) es mayor que el del Contenido de Enseñanza (0,435). Para el Personal Docente, tanto los expertos como los estudiantes están de acuerdo en que el peso de la Pericia Profesional es el más bajo. En resumen, las Cualidades Profesionales en la dimensión del Personal Docente, especialmente la Reflexión sobre la Enseñanza y la Alfabetización Política, son los factores clave que afectan la CE. La Producción Académica de los Estudiantes y los Criterios de Evaluación son los factores centrales en la evaluación del Objetivo de Enseñanza.

Palabras clave: sistema de indicadores de evaluación, calidad de la enseñanza, estudiantes de posgrado, gestión de la salud, delphi

Pesquisa sobre o sistema de indicadores de avaliação da qualidade do ensino para estudantes de pós-graduação em gestão da saúde

Resumo: O objetivo deste estudo foi desenvolver um sistema abrangente de indicadores de avaliação para medir a qualidade do ensino (QE) de estudantes de pós-graduação na área de Gestão em Saúde. O sistema de indicadores foi construído utilizando o Método Delphi, com a participação de 20 especialistas seniores com ampla experiência em educação e pesquisa em gestão em saúde. O sistema de avaliação final foi aplicado em um estudo de caso na Universidade Médica de Guangxi. O peso do Corpo Docente (0,381) e do Objetivo de Ensino (0,381) foi maior do que o do Processo de Ensino (0,237). Na dimensão do Corpo Docente, os especialistas destacaram que as Qualidades Profissionais (0,057) desempenham um papel fundamental na QE, especialmente a Reflexão sobre o Ensino (0,255) e a Alfabetização Política (0,255). Na dimensão do Objetivo de Ensino, a Produção Acadêmica dos Estudantes (0,072) e os Critérios de Avaliação (0,065) foram considerados os fatores centrais. Na

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dimensão do Processo de Ensino, o peso dos Métodos de Ensino (0,565) foi maior do que o do Conteúdo de Ensino (0,435). No Corpo Docente, tanto especialistas quanto estudantes concordaram que o peso da Expertise Profissional é o menor. Em resumo, as Qualidades Profissionais na dimensão do Corpo Docente, especialmente a Reflexão sobre o Ensino e a Alfabetização Política, são os principais fatores que afetam a QE. A Produção Acadêmica dos Estudantes e os Critérios de Avaliação são os fatores centrais na avaliação do Objetivo de Ensino.

Palavras-chave: sistema de indicadores de avaliação, qualidade do ensino, estudantes de pós-graduação, gestão em saúde, delphi

Introduction

The improvement of graduate teaching quality involves various aspects, including coursework, advisor guidance, thesis quality monitoring, and practical training. Among these, coursework is an essential feature of China's degree and graduate education system, serving as a fundamental component to ensure the quality of graduate training. Emphasizing coursework, strengthening curriculum construction, and improving course quality are currently important and urgent tasks in the ongoing reform of graduate education. With the acceleration of higher education expansion and the deepening reform and adjustment of graduate education, the structure and outlook of graduate education in China have undergone profound changes. In January 2015, the Ministry of Education issued the *Opinions on Improving and Strengthening Graduate Curriculum Construction*, stating that training institutions should scientifically recognize the vital role and function of coursework in graduate education, emphasize curriculum construction, fully assume responsibility for curriculum development, and strengthen long-term and systematic planning for curriculum construction. In line with the requirements of the *Opinions*, it is imperative to develop an effective evaluation system for graduate teaching quality.

Social Medicine and Health Service Management is an interdisciplinary field that bridges medicine, social sciences, and management sciences. It encompasses major disciplines and sub-disciplines, including Social Medicine, Health Service Management, Health Economics, Medical Insurance, Public Health Policy, Health Law, Hospital Management, and Medical Ethics. Based on the biopsychosocial medical model, it focuses on social, community, and healthcare institutions and personnel as its primary research objects. This field applies the theories and methods of social sciences and management sciences to clinical medicine, preventive medicine, and health service management. It aims to uncover the impacts of social, cultural, and economic factors on population health, adopt social measures to prevent and control diseases, promote the development and reform of the healthcare sector, and enhance the efficiency and effectiveness of health services. The ultimate goal is to improve public health and quality of life while promoting social and economic development. Against the backdrop of China's strong advocacy for the "Healthy China" initiative, ensuring the quality of talent in health service management is of great significance. Medical universities bear the important responsibility of cultivating talent in Social Medicine and Health Service Management. As an integral part of higher education, graduate education serves as a key platform for cultivating high-level innovative talent. Therefore, ensuring the teaching quality of graduate programs in this field is critical to talent development. The graduate teaching quality evaluation system is an important part of the graduate training framework. It plays a key role in cultivating innovative talent and serves as an essential tool for ensuring and improving the quality of talent training.

Numerous studies have focused on the evaluation indicators of teaching quality. For instance, some studies emphasize outcome-based teaching evaluation, which highlights teaching effectiveness and learning outcomes, with particular attention to how the teaching process enhances students' learning results. For example, Dong et al. (2022) proposed that classroom teaching represents the most essential component of undergraduate education, with its quality directly influencing the effectiveness of talent development*(1)*. Wei Dongting et al. (2020), based on the OBE (Outcome-Based Education) concept and guided by learning outcomes, constructed an evaluation system comprising four dimensions: teaching attitude, teaching content, teaching methods, and teaching effectiveness. Ultimately, 12 key evaluation indicators were identified*(2)*. Tang Jishen and Mo Yi (2020) proposed a cyclical system for evaluation feedback to enhance the effectiveness of online teaching through continuous improvement. Their approach emphasizes the combination of outcome orientation and feedback-driven improvement*(3)*. There is also student-centered teaching evaluation, which focuses on students' feedback as the core. This type of research emphasizes assessing teaching quality from the students' perspective. By understanding students' experiences and needs, it aims to construct a teaching evaluation system that better suits students. For example, Li Zhengang et al. developed a "student-centered" evaluation system based on students' perceptions of a "good teacher" and a "good classroom," covering dimensions such as teaching attitude, teaching content, and teaching ability*(4)*. Zuo Rongxin and Chen Zhaowen (2023) used decision trees and association rules to build a teaching evaluation framework for colleges, studying the relationships between educational factors, educational chain factors, and teaching effects, providing a decision-making framework for teaching quality evaluation and conducting a comprehensive analysis of related factors*(5)*. There is also theory-practice integrated teaching evaluation, which emphasizes the combination of theoretical concepts with the actual teaching process. By integrating diverse data sources and field research, this type of study aims to develop a scientific and effective evaluation system. For example, Shi Xuan et al. (2018) adopted stratified sampling and interview methods to combine evaluation indicators from different institutions. They proposed a multidimensional evaluation system covering teaching design, teaching methods, teaching content, and teaching effectiveness, with a strong emphasis on the integration of theory and practice*(6)*. Wang Liang and Ge Chenran (2021) integrated expert opinions with basic requirements for online teaching, employing the Analytic Hierarchy Process to design a teaching quality evaluation index system. This system comprehensively covers standards including teaching faculty, educational philosophy, teaching methods, instructional objectives, teaching process, educational resources, teaching activities, as well as teaching evaluation and feedback*(7)*. Xue Ning and Yang Xiaodong (2020) developed an online teaching evaluation system that includes pre-class preparation, in-class implementation, and post-class outcomes. By flexibly adjusting the indicators at different teaching stages, the system ensures the integration of theory and practice*(8)*. Additionally, there are teaching evaluations that emphasize multidimensionality and multi-stakeholder participation. These studies integrate multiple evaluation dimensions and the opinions of various stakeholders to construct a comprehensive evaluation system, ensuring the multidimensionality and inclusiveness of teaching evaluations. Qian Dandan et al. (2021) established a "five-in-one" quality evaluation system model encompassing five dimensions: teacher self-evaluation, student evaluation, departmental self-inspection, peer evaluation, and supervisory evaluation. This model provides theoretical support for the paradigm reform and sustainable development of higher education(*9)*.

However, existing studies also have certain limitations. For instance, many evaluations use a "one-form, multi-assessment" system that lacks specificity, failing to distinguish between different disciplines and course types, especially ignoring the differences between theoretical courses and practical courses. This approach makes it difficult to meet the modern educational needs for cultivating diverse and specialized talent*(10)*. In addition, many schools apply unified evaluation indicators across all courses and disciplines, resulting in a lack of specificity. Furthermore, the evaluation of practical teaching is often focused on the final thesis or report, with a significant absence of process-based evaluation and assessments of students' practical abilities. Notably, higher education institutions have paid little attention to the quality assessment of the practical teaching process*(11)*. Teaching evaluation indicators are overly focused on teachers' teaching performance while neglecting students' learning experience. Some evaluation content is too broad, exceeding the scope of what students can accurately evaluate*(12)*. In recent years, with online teaching evolving from a supplementary approach to a routine teaching method, many universities have continued to use evaluation standards originally designed for offline courses to assess online courses. This approach is also inappropriate*(13)*.

Therefore, this study incorporates certain optimizations during its design and implementation. The teaching quality evaluation is specifically targeted at the Social Medicine and Health Service Management discipline, focusing on the evaluation of **o**ffline theoretical courses. The evaluation indicator design is based on three dimensions: Teaching Staff, Teaching Process, and Learning Outcomes. It comprehensively considers all aspects of the teaching process. To establish the evaluation system, the study engaged senior expert teachers in this field using the Delphi method, forming a multi-level teaching evaluation indicator system with three levels of indicators. On this basis, student attitudes were solicited, and the commonalities and differences in indicator weights between the two groups (teachers and students) were analyzed to explore students' recognition of the indicator system.

Methods

Literature Research Method

This study uses keywords such as Social Medicine and Health Service Management, graduate students, teaching quality, and indicator system construction to search relevant online databases, including CNKI (China National Knowledge Infrastructure), VIP Database, Wanfang Data, China Biomedical Literature Database (CBMdisc), PubMed, Web of Science, and Ovid. The collected literature is organized, reviewed, and analyzed, with relevant studies summarized according to publication year and type. The objectives of talent training in Social Medicine and Health Service Management, as well as the societal needs for such talents, are analyzed and summarized. From the perspectives of promoting the development and reform of the healthcare system, improving the efficiency and effectiveness of health services, and enhancing public health and quality of life, the key areas for graduate education in Social Medicine and Health Service Management are comprehensively explored.

Selection of Experts for Delphi Consultation
Experts specializing in social medicine, health service management, or public administration education were selected from various universities with graduate programs in Health Management. These experts were required to have at least 10 years of relevant work experience in higher medical institutions or research institutions and to hold a position of associate professor or above. A total of 20 experts were selected as consultation participants.

Consultation Questionnaire and Data Processing
The main content of the questionnaire includes basic information about experts, evaluation of the importance of indicators, familiarity with indicators, and the basis for judgment. The questionnaire design also incorporates modification, deletion, and addition of indicators at all levels, and requires experts to assess the importance of newly added indicators. Additionally, an "other comments" section is included to allow experts to provide suggestions and opinions. The importance of indicators is evaluated using a Likert 5-point scale(14), where "very important" = 5 points, "important" = 4 points, "moderately important" = 3 points, "slightly important" = 2 points, and "not important" = 1 point. The familiarity with indicators is also assessed using a 5-level scale(15): "very familiar" = 1.0, "relatively familiar" = 0.8, "familiar" = 0.6, "slightly familiar" = 0.4, and "unfamiliar" = 0.2. The basis for judgment is categorized into four types: practical experience, theoretical analysis, reference literature, and intuitive judgment. The influence of these four bases is rated as high, medium, or low, with different quantification values assigned to each level(16) (see Table 1).

Table 1. Assignment of Influence Levels for Experts' Basis of Judgment

Basis for Judgment	High	Medium	Low
Practical Experience	0.5	0.4	0.3
Theoretical Analysis	0.3	0.2	0.1
Reference Literature	0.1	0.1	0.1
Intuitive Judgment	0.1	0.1	0.1

Data Collection

The Delphi method typically requires at least 2 rounds of consultation, and this study plans to conduct 2 rounds of expert consultation. The research team will distribute the expert consultation questionnaire to the selected experts via email or postal mail, requesting the experts to return their responses within two weeks. If the questionnaires are sent by postal mail, an envelope with the researcher's mailing address and prepaid postage will be included to facilitate the return of the completed questionnaire. The research team will review all returned questionnaires. If any questionnaire does not meet the completion criteria, the research team will contact the experts for corrections. If corrections cannot be made, the questionnaire will be excluded from the study.

Survey of Student Opinions

Based on the final evaluation indicator system established by the experts, a student survey questionnaire was designed. In this process, students were treated as "experts" to obtain their feedback and compare the differences in the focus of students and experts. A convenience sampling method was adopted, with graduate students from the Health Service Management program at Guangxi Medical University as the survey participants. A total of 47 questionnaires were distributed to first-year to third-year graduate students, and 42 valid questionnaires were collected, resulting in a response rate of 89.4%. The student questionnaire was created using the “Questionnaire Star” platform, allowing students to scan a QR code and complete the questionnaire online.

Ethical Considerations

All participants received detailed information about the study objectives, procedures, and their rights through an electronic document. They provided their consent by signing the electronic form or confirming agreement via a secure online platform. This process ensured that all participants were fully informed and voluntarily participated in the study. Confidentiality and anonymity of the experts’ responses were strictly maintained, with no personal identifying information collected. All data were securely stored and used solely for research purposes. This study was approved by the Guangxi Medical University Ethics Committee (approval No.KY0310)

Analysis of Survey Data

The database is established using Epidata 3.0 software. Data from the returned questionnaires is entered twice by two independent researchers to ensure accuracy. Discrepancies between the two entries are checked against the original questionnaire and corrected accordingly. SPSS 19.0 software is used for statistical description and parameter estimation of the data.

Results

Preliminary Construction of the Teaching Quality Evaluation Indicator System

This study uses keywords such as Social Medicine and Health Service Management, graduate students, teaching quality, and indicator system construction to search relevant online databases, including CNKI (China National Knowledge Infrastructure), VIP Database, Wanfang Data, China Biomedical Literature Database (CBMdisc), PubMed, Web of Science, and Ovid. The collected literature is organized, reviewed, and analyzed, with relevant studies summarized according to publication year and type. The objectives of talent training in Social Medicine and Health Service Management, as well as the societal needs for such talents, are analyzed and summarized. From the perspectives of promoting the development and reform of the healthcare system, improving the efficiency and effectiveness of health services, and enhancing public health and quality of life, the key areas for graduate education in Social Medicine and Health Service Management are comprehensively explored. Based on these findings, a preliminary framework for the teaching quality evaluation indicator system for graduate students majoring in Health Service Management is developed. After consultation with senior professors in the field of graduate education, an initial version of the evaluation indicator system is proposed. The system includes three primary indicators, six secondary indicators, and 28 tertiary indicators, as shown in Figure 1.

Construction of the Indicator System Based on the Delphi Expert Consultation Method

(1) Selection of Delphi Experts

Experts were selected from medical universities in Guangxi (including Guangxi Medical University, Guangxi University of Chinese Medicine, and Guilin Medical University), universities outside the province that offer Health Service Management programs (such as Wuhan University and Sun Yat-sen University), as well as health administrative departments. A total of 20 experts were selected to participate in the Delphi expert consultation, which was conducted from December 2021 to April 2022. The experts’ average age was (42 ± 8.34) years, with an average of (17.30 ± 10.17) years of work experience. The panel included 8 experts with senior professional titles, 6 with associate senior titles, and 6 with intermediate titles. In terms of educational background, 11 experts held doctoral degrees, and 9 held master’s degrees. Further details are provided in Table 2.

Table 2. Expert Profile

Category	N	%
Age (years)		
≤35	5	25
35~	7	35
45~	5	25
≥55	3	15
Years of Service		
≤10	5	25
10~	7	35
20~	4	20
≥30	4	20
Education		
Doctorate	11	55
Master's Degree	9	45
Professional Title		
Senior	8	40
Associate Senior	6	30
Intermediate	6	30
Position		
Division Level	4	20
Section Level	4	20
Other	12	60
Work Field		
Medical Higher Education	13	65
Health Administration	4	20
Hospital Management	1	5
Other	2	10

(2) Indicator Screening and Revision

The initial indicator system framework is subjected to the first round of Delphi expert consultation, and indicators are screened based on specific criteria. Indicators are retained if the mean full-score rate of the indicator exceeds the threshold and if the coefficient of variation (CV) is below the corresponding threshold. Expert feedback is also considered, and indicator screening and revisions are conducted following group discussions. For primary indicators, the full-score rate must be greater than 0.73, and the coefficient of variation must be less than 0.133 to be recommended for retention. For secondary indicators, the full-score rate must be greater than 0.65, and the coefficient of variation must be less than 0.138. For tertiary indicators, the full-score rate must be greater than 0.55, and the coefficient of variation must be less than 0.161. The threshold values for each level of indicators are detailed in Table 3.

After the first round of Delphi expert consultation, adjustments were made to the indicators based on expert ratings and revision suggestions. This process resulted in a new teaching quality evaluation indicator system for graduate students majoring in Health Service Management, which was then used for the second round of Delphi expert consultation. The experts for the second round were the same as those in the first round. Through statistical analysis of the second-round expert consultation questionnaire, 6 indicators were deleted, including Teaching Progress, Teaching Discipline, Teacher's Appearance, Innovation in Teaching Approaches, Design of Assignments, and Exam Difficulty. Two indicators were modified, and 5 new indicators were added, resulting in an updated teaching quality evaluation indicator system for graduate students majoring in Health Service Management.

(3) Calculation of Weights for the Evaluation Indicator System

The coefficient of variation method is used in this study to calculate the weight of each indicator.

Table 3. Screening Thresholds for Indicators in the First Round of Expert Consultation

Indicator	Full Score Rate			Coefficient of Variation		
	Mean	SD	Threshold	Mean	SD	Threshold
Primary Indicator	0.78	0.06	0.73	0.106	0.027	0.133
Secondary Indicator	0.65	0.09	0.56	0.120	0.018	0.138
Tertiary Indicator	0.55	0.15	0.41	0.137	0.025	0.161

Table 4. Weights of the Teaching Quality Evaluation Indicator System for Graduate Students Majoring in Social Medicine and Health Service Management

Primary Indicator	Secondary Indicator	Tertiary Indicator	Weight Coefficient	Combined Weight
Teaching Staff	Professional Qualities	Professional Expertise	(0.125)	(0.028)
(0.381)	(0.587)	Academic Expertise	(0.174)	(0.039)
		Professional Ethics and Pedagogical Style	(0.191)	(0.043)
		Teaching Reflection	(0.255)	(0.057)
		Political Literacy	(0.255)	(0.057)
	Teaching Attitude	Language Proficiency	(0.367)	(0.058)
	(0.413)	Classroom Presence	(0.316)	(0.050)
		Instructional Planning	(0.316)	(0.050)
Teaching Process	Teaching Methods	Effectiveness of Teaching Methods	(0.258)	(0.035)
(0.237)	(0.565)	Teacher-Student Interaction	(0.227)	(0.030)
		Emphasis on Practical Application	(0.257)	(0.034)
		Integration of Ideological and Political Education	(0.257)	(0.034)
	Teaching Content	Logical Organization	(0.145)	(0.015)
	(0.435)	Emphasis on Key and Difficult Points	(0.099)	(0.010)
		Content Coherence	(0.122)	(0.013)
		Content Updates	(0.125)	(0.013)
		Integration of Case Studies	(0.122)	(0.013)
		Integration of Policies	(0.122)	(0.013)
		Highlighting Local Disciplinary Features	(0.121)	(0.012)
		Integration of Research	(0.145)	(0.015)
Teaching Target	Learning Outcomes	Capability Enhancement	(0.225)	(0.041)
(0.381)	(0.482)	Knowledge Application	(0.206)	(0.038)
		Learning Motivation	(0.250)	(0.046)
		Interest in Lectures	(0.319)	(0.059)
	Student Assessment	Student Evaluations	(0.308)	(0.061)
	(0.518)	Assessment Criteria	(0.328)	(0.065)
		Students' Research Output	(0.365)	(0.072)

The coefficient of variation method determines indicator weights based on the variability of indicator data, reflecting the objective information on the variation of indicator data. It is an objective method for determining weights. For the same evaluation indicator, the greater the difference in the attribute values of each scheme, the more important the indicator is in the comprehensive selection, and the more information it provides to decision-makers*(17)*. Therefore, the weight of

Table 5. Weights of the Teaching Quality Evaluation Indicator System for Graduate Students in Health Service Management (from Students' Perspective)

Primary Indicators	Secondary Indicators	Tertiary Indicators	Weight Coefficient	Combined Weight
Teaching Staff	Professional Qualities	Professional Expertise	(0.140)	(0.022)
(0.322)	(0.487)	Academic Expertise	(0.176)	(0.028)
		Professional Ethics and Pedagogical Style	(0.201)	(0.031)
		Teaching Reflection	(0.224)	(0.035)
		Political Literacy	(0.258)	(0.040)
	Teaching Attitude	Language Proficiency	(0.310)	(0.051)
	(0.513)	Classroom Presence	(0.307)	(0.051)
		Instructional Planning	(0.384)	(0.063)
Teaching Process	Teaching Methods	Effectiveness of Teaching Methods	(0.175)	(0.024)
(0.288)	(0.476)	Teacher-Student Interaction	(0.269)	(0.037)
		Emphasis on Practical Application	(0.257)	(0.035)
		Integration of Ideological and Political Education	(0.300)	(0.041)
	Teaching Content	Logical Organization	(0.130)	(0.020)
	(0.524)	Emphasis on Key and Difficult Points	(0.119)	(0.018)
		Content Coherence	(0.128)	(0.019)
		Content Updates	(0.129)	(0.019)
		Integration of Case Studies	(0.120)	(0.018)
		Integration of Policies	(0.122)	(0.018)
		Highlighting Local Disciplinary Features	(0.129)	(0.020)
		Integration of Research	(0.122)	(0.018)
Teaching Target	Learning Outcomes	Capability Enhancement	(0.214)	(0.032)
(0.390)	(0.386)	Knowledge Application	(0.201)	(0.030)
		Learning Motivation	(0.284)	(0.043)
		Interest in Lectures	(0.301)	(0.045)
	Student Assessment	Student Evaluations	(0.355)	(0.085)
	(0.614)	Assessment Criteria	(0.355)	(0.085)
		Students' Research Output	(0.289)	(0.069)

each indicator is determined by the amount of information it provides to decision-makers. The calculation formula is not elaborated here, and the summary of the indicator system and its corresponding weights is shown in Table 4.

Coefficient of Expert Authority

The level of expert enthusiasm is reflected by the questionnaire response rate. In this study, the response rate for both rounds of consultation was

100%, indicating a high level of expert interest and cooperation with the study, which enhances the credibility of the results. The level of expert authority is measured using the expert authority coefficient (Cr), which is calculated as the arithmetic mean of the Coefficient of Expert Judgment (Ca) and the Coefficient of Expert Familiarity (Cs). The authority coefficient ranges from 0 to 1, with higher values indicating greater expert authority. Generally, a Cr value greater than 0.7 is considered acceptable(18,19). In this study, the expert authority coefficient was 0.864 in the first round and 0.939 in the second round, indicating a high level of expert authority.

Preferences of Graduate Students in the Health Service Management Program

Based on the previously constructed teaching quality evaluation indicator system for the Health Service Management program, a questionnaire was developed for graduate students. The weights of each indicator were calculated using the coefficient of variation method, and the results are presented in Table 5. A comparison of the primary indicators reveals that both experts and students assigned the lowest weight to Teaching Process. However, students tended to regard Teaching Staff as the key focus of teaching quality evaluation, while experts considered both Teaching Staff and Teaching Target to be equally important for evaluation purposes.

Discussion

Research Output and Course Assessment Criteria are Key to the Evaluation of Teaching Target Compared with the Teaching Process, the dimensions of Teaching Staff and Teaching Target hold a higher weight in the teaching quality evaluation indicator system. Experts generally believe that teachers and students are the key determinants of teaching quality throughout the teaching process, while the process itself is perceived as relatively less “important.” Notably, under the dimension of Teaching Target, the importance of Student Assessment has been unanimously recognized by experts. The focus of student assessment is primarily on students’ research output, followed by the design of assessment criteria. Participating in research activities allows graduate students to access cutting-edge knowledge and equipment, collaborate with professors, publish papers, attend conferences, build essential networks, and explore post-graduation career paths. These experiences are crucial for graduate students’ academic and career development. Studies have shown that students who publish more papers, participate in more research projects, spend more time on study and research beyond classroom learning, and engage more frequently with supervisors tend to achieve greater success in their future careers*(20)*. Quality is the lifeline of graduate education and the fundamental guarantee for its sustainable development*(21)*. Research capability is the most direct manifestation of quality*(22)*. The 2020 National Graduate Education Conference explicitly stated that research should be regarded as a fundamental indicator for assessing the quality of graduate students. Faced with ongoing enrollment expansion and system reforms, graduate education is under unprecedented pressure. Placing a high priority on cultivating graduate students’ research capabilities is undoubtedly of profound strategic significance.

Traditional assessment methods are primarily end-of-course summative exams. The majority of courses use final exam results as the primary measure of students’ learning outcomes. Apart from experimental courses, most teaching processes lack formative assessment components. Therefore, in most cases, it is advisable to adopt a diversified assessment model that combines formative assessment with summative assessment*(23)*. The *Opinions on Improving and Strengthening Graduate Curriculum Construction(24)* proposes that the design of assessment methods should be based on the characteristics of course content, teaching requirements, and instructional methods. It emphasizes the diversification, effectiveness, and feasibility of assessment formats. Research shows that after implementing a system of combining process-based and outcome-based assessments, students pay more attention to each stage of the course, fostering a self-directed learning culture. As a result, student performance improves significantly, the number of students failing courses is notably reduced, and professional competence and innovative abilities are significantly enhanced*(25)*.

Therefore, in assessing students, reasonable assessment content and score allocation are essential for comprehensively evaluating graduate students' learning outcomes.

Teacher Competence is a Key Factor in Improving Teaching Quality

Experts emphasize the role of the Teaching Staff dimension in improving teaching quality, with a particular focus on Professional Qualities, where Teaching Reflection and Political Literacy are considered the most critical components. Teaching reflection is a comprehensive and profound examination, contemplation, and improvement of the educational process, recognized as a practical and effective approach for teachers to pursue professional development*(26)*. Reflective teaching promotes the effectiveness of graduate course instruction and facilitates the professional growth of graduate instructors. By improving teaching quality, reflective teaching can attract high-quality students and enhance the academic reputation of the discipline*(27)*.

Teachers not only serve as knowledge transmitters but also undertake the responsibility of ideological and political education. Cases of inappropriate political conduct in the classroom are not uncommon. For example, on September 18, 2017, a mathematics teacher from the School of Science at a university in China was reported for making inappropriate comparisons between the Japanese and Chinese ethnic groups while teaching a **P**robability Theory course. The students in the class filed a complaint with the university president regarding the teacher's discriminatory remarks*(28)*. This highlights the importance of Political Literacy as an essential professional quality for teachers. It is also a core component of teachers' Professional Ethics, serving as a guiding principle for teachers' professional development and shaping their capacity to fulfill the educational mission*(29,30)*.

The Effective Use of Teaching Methods is More Important than Teaching Content in the Teaching Process

The Teaching Process dimension is the least weighted among the primary indicators. This dimension includes two secondary indicators: Teaching Methods and Teaching Content. Analysis of the weight values in the evaluation system shows that Teaching Methods (weight 0.565) are more important than Teaching Content (weight 0.435). Studies have shown that the use of diverse and targeted teaching methods can better meet students' individualized learning needs and effectively promote the transfer and application of knowledge inside and outside the classroom. For example, in problem-based learning environments, teaching methods are more effective than content alone in stimulating students' critical thinking and problem-solving skills*(31,32)*. Well-designed teaching methods can help students actively explore and internalize knowledge in complex situations, rather than merely memorizing or repeating it. Research shows that the implementation of innovative teaching methods not only engages students but also facilitates a deeper understanding of theoretical concepts, demonstrating that effective teaching strategies can enhance learning outcomes more than the content itself*(33)*.

However, students tend to place more emphasis on the value of Teaching Content (weight 0.524) than on Teaching Methods (weight 0.476). This may stem from their interest in the systematic and cutting-edge nature of the content, as they expect the knowledge they acquire to directly contribute to their research and career development. This difference in perspective reveals a key issue in educational practice: experts prioritize how to teach, while students focus on what is learned. The findings underscore the need to integrate teaching methods and content to achieve both student-centered learning and teaching goals.

The Professional Background of Teachers is Not Considered a Key Evaluation Factor
It is also worth noting that although Professional Qualities are a key consideration in the evaluation of Teaching Staff, the indicator of Professional Expertise has the lowest weight under this dimension. This is consistent with the views of both experts and students. This finding suggests that, within the field of Social Medicine and Health Service Management, a teacher's professional background is not regarded as "particularly important." This may be related to the interdisciplinary nature of Social Medicine and Health Service Management, which integrates perspectives from

healthcare, social sciences, and management. The field studies the relationships between medicine, society, communities, healthcare institutions, and health systems*(34)*. As a result, teachers from different academic backgrounds may have different interpretations of the discipline, providing students with diverse perspectives that can broaden their horizons and inspire greater interest in learning. This may explain why students are less concerned about the professional background of their instructors.

Advantages and Limitations

Overall, this study constructs a classroom teaching quality evaluation indicator system for graduate students majoring in Social Medicine and Health Service Management, providing a theoretical reference for evaluation research in this field. The differences in indicator weights between experts and students reveal that experts tend to construct evaluation indicators based on the professional characteristics and teaching practices of the discipline, while students' perspectives are more rooted in their personal learning experiences. Students also seek to reflect on their role in the teaching evaluation process.

However, this study has certain limitations. For instance, when assessing students' perceptions of the evaluation indicator system, only students from one medical university were surveyed, limiting the scope of validation. In future research, surveys will be extended to graduate students from other medical universities in Guangxi to gain a broader understanding of the acceptance and recognition of the indicator system.

Authors contributions

Hongda Gao and He Chen generated the initial idea and participated in the design of the work. Nan Jiang analyzed the data and participated in the design of the data. Hongda Gao, He Chen and Nan Jiang contributed equally. Tingting Xu participated in the conception and design of the work. All authors reviewed the manuscript.

Ethics approval and consent to participate

This study was approved by Guangxi Medical University Ethics Committee (approval No.KY0310). Informed consent was obtained from all participants.

Consent for publication

Not applicable.

Availability of data and materials

All data relevant to the study are included in the article.

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Competing interests

The authors declare that they have no competing interests.

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PRACTICAS ÉTICAS DE LAS TESIS DE ODONTOLOGÍA DE UNA UNIVERSIDAD PÚBLICA DEL SUR DEL PERÚ (2016-2023)

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Resumen: El objetivo de la presente investigación fue determinar las prácticas éticas en las tesis de Odontología de una universidad pública del sur del Perú entre 2016 y 2023, con el fin de mejorar estas prácticas en la investigación odontológica y promover un entorno académico más responsable. El método utilizado fue de tipo cuantitativo, descriptivo y retrospectivo, utilizando datos públicos de 150 tesis del repositorio institucional de la Universidad Nacional Jorge Basadre Grohmann. Las variables analizadas incluyeron la ética en la recolección de datos, manipulación de datos, colaboración y autoría, y difusión de resultados. Los datos fueron analizados usando estadísticas descriptivas con el programa IBM SPSS Statistics versión 26. Los hallazgos muestran que la totalidad de las tesis no fueron revisadas por un comité de ética, el 52,2% no presentó constancia de ejecución de la institución, el 67% reconoció adecuadamente las contribuciones de asesores y colaboradores, y el 100% no comunicó los resultados a la población de estudio. Además, la mayoría de las tesis (91,3%) fueron de tipo básico, lo cual contrasta con la política universitaria que promueve la investigación aplicada. En conclusión, las prácticas éticas en las tesis de Odontología de esta universidad son deficientes, especialmente en la revisión ética y la difusión de resultados. Se recomienda fortalecer la formación ética y establecer convenios con comités de ética reconocidos para garantizar la integridad y responsabilidad en la investigación.

Palabras clave: revisión ética, ética en investigación, tesis académica, comités de ética en investigación

Ethical practices of the Dentistry theses of a public university in southern Peru (2016-2023)

Abstract: The objective of the present research was to determine the ethical practices in the dentistry theses of a Public University in Southern Peru between 2016 and 2023, to improve ethical practices in dental research and promote a more responsible academic environment. The method used was quantitative, descriptive, and retrospective, utilizing public data from 150 theses in the institutional repository of the National University Jorge Basadre Grohmann. The variables analyzed included ethics in data collection, data manipulation, collaboration and authorship, and dissemination of results. The data were analyzed using descriptive statistics with IBM SPSS Statistics version 26. The findings show that 100% of the theses were not reviewed by an ethics committee, 52.2% did not present an execution certificate from the institution, 67% adequately recognized the contributions of advisors and collaborators, and 100% did not communicate the results to the study population. Additionally, most of the theses (91.3%) were of a basic type, which contrasts with the university policy that promotes applied research. The ethical practices in the dentistry theses of this university are deficient, especially in ethical review and result dissemination. It is recommended that ethical training be strengthened and agreements established with recognized ethics committees to ensure integrity and responsibility in research.

Keywords: ethical review, ethics research, academic dissertation, ethics committees research

Práticas éticas das teses de Odontologia de uma universidade pública no sul do Peru (2016-2023)

Resumo: O objetivo desta pesquisa foi determinar as práticas éticas nas teses de Odontologia de uma universidade pública no sul do Peru entre 2016 e 2023, a fim de melhorar essas práticas na pesquisa odontológica e promover um ambiente acadêmico mais responsável. O método utilizado foi quantitativo, descritivo e retrospectivo, utilizando dados públicos de 150 teses do repositório institucional da Universidade Nacional Jorge Basadre Grohmann. As variáveis analisadas incluíram ética na coleta de dados, manipulação de dados, colaboração e autoria e divulgação dos resultados. Os dados foram analisados por meio de estatística descritiva com o programa IBM SPSS Statistics versão 26. Os achados mostram que todas as teses não foram revisadas por um comitê de ética, 52,2% não apresentaram comprovação da execução da instituição, 67% reconheceram adequadamente as contribuições dos orientadores e colaboradores e 100% não comunicaram os resultados à população estudada. Além disso, a maioria das teses (91,3%) era do tipo básico, o que contrasta com a política universitária de fomento à pesquisa aplicada. Conclui-se que as práticas éticas nas teses de Odontologia desta universidade são deficientes, principalmente na revisão ética e na divulgação dos resultados. Recomenda-se fortalecer o treinamento ético e estabelecer acordos com comitês de ética reconhecidos para garantir a integridade e a responsabilidade na pesquisa.

Palavras-chave: revisão ética, ética em pesquisa, tese acadêmica, comitês de ética em pesquisa

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Introducción

En la última década, el campo de la odontología ha experimentado un notable crecimiento en la producción de investigaciones, reflejando un compromiso cada vez mayor con el avance del conocimiento y la práctica clínica. Sin embargo, a medida que la investigación se expande, también surgen preocupaciones éticas que deben ser abordadas con rigor desde la formación de un investigador; esto se presenta las universidades, donde los estudiantes tienen sus primeras experiencias en investigación. La ética en la investigación es un componente crucial que garantiza la integridad, la transparencia y la responsabilidad en el proceso investigativo, y su análisis se vuelve especialmente relevante en contextos académicos específicos.

Esta investigación aborda diferentes aspectos éticos que deben tenerse en cuenta durante el proceso de una investigación, en el que se obtiene y gestiona la información, asegurando se obtenga de manera honesta y transparente, garantizando sea tratada con integridad, que no se modifique ni se manipule, de manera que se alteren los resultados y se asegure que cada contribución sustancial sea debidamente acreditada y se divulgue de manera precisa, sin tergiversaciones. Este estudio se enfoca en analizar los aspectos éticos de las tesis de odontología de una universidad pública del sur del Perú, abarcando un periodo de siete años, desde 2016 hasta 2023. La investigación se estructura en torno a cuatro dimensiones clave de la ética en la investigación: la ética en la recopilación de datos, la ética en la manipulación de datos, la ética en la colaboración y autoría, y la ética en la difusión de resultados.

La presente investigación tiene como objetivo determinar las prácticas éticas en las tesis de Odontología de una universidad pública del sur del Perú durante los años 2016-2023, y con los resultados se pretende contribuir a la mejora de las prácticas éticas en la investigación odontológica y promover un entorno académico más riguroso y responsable.

Ética en la recopilación de datos

La ética en la recopilación de datos es un aspecto fundamental que garantiza que los métodos de investigación sean moralmente aceptables y respetuosos con los derechos de los participantes. Una revisión ética por un comité especializado es un paso esencial para asegurar que el diseño de la investigación y los métodos de recolección de datos cumplan con los estándares éticos y legales vigentes. Esto incluye asegurar que los participantes sean tratados con respeto, que sus derechos y dignidad sean preservados, y que se obtenga su consentimiento informado de manera adecuada. En el contexto de la odontología, donde la recolección de datos puede implicar procedimientos clínicos o la recopilación de información sensible, la supervisión ética es crucial para proteger a los pacientes y participantes. Lamentablemente, en las tesis y publicaciones médicas alemanas no se menciona la aprobación ética y el 58,7% de los casos cumplen los criterios de la Declaración de Helsinki*(1)*, en cambio otro estudio reportó que el 24% de las propuestas fueron aprobadas sin solicitud de cambios o aclaraciones por parte de los cuatro comités locales de ética*(2)*. Por otro lado, en una revisión sistemática, solo el 2% de los científicos admite haber falsificado la investigación al menos una vez y hasta el 34% otras prácticas de investigación cuestionables, pero las frecuencias reales de mala conducta podrían ser más altas*(3)*. Por tal motivo los comités de ética juegan un papel central en la revisión y aprobación de los proyectos de investigación, asegurando que se cumplan los estándares éticos y científicos, la protección de los derechos humanos y el bienestar de los sujetos de investigación, sobre la base de la autonomía, la justicia, la beneficencia y no maleficencia, la confidencialidad y la honestidad*(4,5)*.

La aprobación de los comités de ética es esencial para cualquier estudio que implique intervenciones en humanos, garantizando el cumplimiento de los estándares éticos locales e internacionales*(6,7)*. Estos comités evalúan y aprueban los protocolos de investigación, garantizando el respeto hacia los sujetos de investigación y legitimando el proceso*(8,9)* y, por consecuencia, promueven la confianza pública en la investigación científica al garantizar que se realiza de manera ética y transparente*(10,11)*. Estos comités deben estar en constante reforma para mejorar su capacidad de supervisión, en esta era de la ciencia de datos intensiva, incluyendo la formación en ética de grandes datos y la colaboración con expertos externos*(12,13)*.

Ética en la manipulación de datos

Se refiere a la gestión responsable y honesta de la información recolectada durante el proceso de investigación. Es fundamental que los investigadores presenten la constancia de ejecución de la institución donde se realizó la investigación, lo cual asegura que la institución respalda la investigación y que se ha seguido un protocolo ético. Esto también implica que los datos han sido tratados con integridad, sin manipulación o distorsión para favorecer ciertos resultados.

La presentación de constancias y otros documentos de respaldo es una práctica importante para la transparencia y la rendición de cuentas. Además, es vital que los datos se almacenen y se manejen de manera segura para proteger la privacidad de los participantes. Cualquier violación de estos principios puede resultar en daños a la reputación académica y profesional de los investigadores, además de posibles repercusiones legales y éticas.

Ética en la colaboración y autoría

La colaboración y autoría en la investigación deben reflejar una distribución justa del crédito y la responsabilidad. El reconocimiento adecuado de las contribuciones de todos los involucrados en una investigación es un principio clave en la ética de la autoría. Esto incluye dar crédito a los asesores, coautores y cualquier otra persona que haya contribuido de manera significativa al desarrollo de la investigación. La omisión de estos créditos constituye una falta ética y puede ser considerada como una forma de plagio o usurpación de autoridad. Es esencial que las universidades y los comités de ética promuevan una cultura de colaboración justa y transparente, en la que se reconozca todas las contribuciones de manera equitativa. Hacerlo puede aumentar la validez de la investigación y la relevancia de las intervenciones desarrolladas*(14)*.

Ética en la difusión de resultados

La difusión ética de los resultados es el último eslabón en la cadena de responsabilidad ética en la investigación. Esto implica no solo la publicación de los hallazgos de manera honesta y precisa, sino también la comunicación de estos resultados a los participantes y la comunidad en general, especialmente si los resultados pueden tener implicaciones prácticas o de salud pública. Los investigadores tienen la obligación ética de difundir los resultados de sus estudios, sean positivos, negativos o inconclusos, de manera precisa y transparente.

Es crucial que los investigadores muestren evidencia que los resultados han sido comunicados a la población de estudio, ya sea a través de presentaciones, informes o publicaciones accesibles. Esto no solo cierra el ciclo de la investigación de manera ética, sino que también fortalece la confianza del público en la ciencia y en los investigadores. La falta de transparencia en esta etapa puede llevar a malas interpretaciones o la difusión de información inexacta, lo que puede tener consecuencias perjudiciales*(15)*.

Métodos

Se trata de una investigación con un enfoque cuantitativo, con un nivel descriptivo y tipo retrospectivo, en la que la variable principal fue determinar las prácticas éticas de las tesis de Odontología de una universidad pública del sur del Perú durante los años académicos 2016-2023, tiempo marco disponible hasta el momento en que se realizó esta investigación. El propósito es contribuir a la mejora de las prácticas éticas en la investigación odontológica y promover un entorno académico más riguroso y responsable. El acceso a los datos es libre y de dominio público y éstos se obtuvieron del repositorio institucional de una universidad pública del sur del Perú, que se define como un almacén digital para hacer pública la producción académica y los resultados de las investigaciones por su comunidad*(16)*. Estos datos fueron utilizados respetando el orden cronológico de su publicación, correspondiendo el dato final a el último trabajo de tesis publicado para 2023.

Las variables secundarias están suscritas en el formato de tesis de la universidad (recolección de datos, proceso de datos, colaboración y autoría y difusión de resultados) y se establecieron considerando la “declaración de Helsinki de la Asociación Médica Mundial —principios éticos para las investigaciones médicas en seres humanos”*(17)*. Estos datos son de dominio público y fueron recolectados 115 tesis (trabajos de investigación) del repositorio de la Universidad Nacional Jorge Basadre Grohmann de Tacna, ubicada en la Región Sur del Perú.

Se clasificó a los trabajos de tesis como básicos —aquellos que tuvieron una intencionalidad netamente exploratoria o descriptiva— y aplicados —los que pretenden generar innovación y tecnología*(18)*. Esta investigación se desarrolló dentro del plan de mejora establecido por la Universidad para la identificación de brechas, en adecuación a la Resolución de Consejo Directivo de la Superintendencia Nacional de Educación Superior Universitaria (SUNEDU), en la que se aprobó los "Estándares para la creación de facultades y escuelas profesionales"*(19)*.

Para la descripción de las variables se utilizó estadísticos descriptivos a través del establecimiento de frecuencias y porcentajes mostradas en tablas con los valores imputados para cada uno de ellos, generándose una tabla separada para cada variable con la finalidad de encontrar patrones o tendencias en cada una de ellas*(20)*. El análisis estadístico se realizó a través del programa IBM SPSS Statictics, versión 26.

Resultados

El presente estudio muestra que, en los estudiantes de Odontología, en los últimos ocho años, hay una clara tendencia a realizar estudios de tipo básico; tal como se muestra en la tabla 1.

Tabla 1. Estadística descriptiva de los tipos de estudio

	F	%
Básico	105	91.3
Aplicado	10	8.7
Total	115	100.0

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En la tabla 2 se observa que ningún trabajo de investigación de los estudiantes de Odontología fue revisado por algún comité de ética.

Tabla 2. Ética en la recopilación de datos

	F	%
Si	00	0.0
No	115	100.0

En la tabla 3 se observa que la mayoría de trabajos de investigación no evidenció en su informe algún tipo de constancia de ejecución otorgada por la institución donde se realizó el levantamiento de los datos.

Tabla 3. Ética en la manipulación de datos

	f	%
Si	55	47.8
No	60	52.2
Total	115	100.0

La tabla 4 muestra que un mayor porcentaje de los estudios realizados por los estudiantes de Odontología brindó algún tipo de crédito, agradecimiento o reconocimiento al asesor y demás involucrados en la investigación.

Tabla 4. Ética en la colaboración y autoría

	f	%
Si	77	67.0
No	38	33.0
Total	115	100.0

Por último, en la tabla 5 se presenta que el total de las investigaciones de los estudiantes de Odontología no evidenció algún tipo de la comunicación de los resultados a la población de estudio. Siendo esto de suma importancia, al ser trabajos de investigación de una profesión médica que generalmente tienen implicaciones de salud pública.

Tabla 5. Ética en la difusión de resultados

	f	%
Si	0	0.0
no	115	100.0
Total	115	100.0

Discusión

El objetivo principal de nuestro trabajo fue determinar las prácticas éticas de las tesis de Odontología de una universidad pública del sur del Perú durante 2016-2023, para lo cual consideramos de importancia establecer el tipo de estudio, si fue revisado por algún comité de ética, si presentó la constancia de ejecución de la institución en la que se realizó la investigación, si brinda los créditos y reconocimientos al asesor y demás involucrados en la investigación, y si muestra evidencia en la comunicación de sus resultados a la población de estudio.

Obtuvimos como resultado que el tipo de estudio más frecuente fue el de tipo básico, lo que podría contradecirse con la política establecida por la ley universitaria peruana N°.30.220 que establece que es papel de las universidades idear respuestas viables a los problemas que bloquean el desarrollo socioeconómico de un país, tal como lo cita Hernández*(21)*. Asimismo, la ley resalta la trascendencia de la integración de los procesos de enseñanza aprendizaje y las competencias de cada especialidad para generar nuevo conocimiento utilizando el método científico, que permita generar innovaciones tecnológicas y promover el vínculo Estado-universidad-empresa, como propone Ramírez y García, en su artículo “Alianza Universidad-Empresa-Estado: una estrategia para promover la innovación”*(22)*. En este contexto, consideramos se debiera dar un mayor impulso al desarrollo de a investigación aplicada.

Hemos podido evidenciar, asimismo, que el total de los trabajos de investigación no pasó la revisión por algún comité de ética, siendo este un requisito fundamental para que se garantice que los métodos de investigación sean moralmente aceptables y respetuosos con los derechos de los participantes, resultados totalmente diferentes con los encontrados por Vidal Anzardo y Margot Lima en su trabajo “Evaluación de la dimensión ética y metodológica de los protocolos de investigación exonerados de revisión en el comité de ética de una universidad peruana”, que encontró que el 85,8% de los trabajos que requerían consentimiento y asentimiento informado, lo tenían*(23)*. Consideramos que debe subsanarse este aspecto, estableciendo convenios con comités de ética reconocidos.

Respecto de la presentación de constancia de ejecución del levantamiento de datos, el 52,2% no presentó la constancia otorgada por la institución en la que se realizó el levantamiento de los datos, lo que se contradice con lo establecido por la directiva para la presentación, aprobación, ejecución, seguimiento y finalización de proyectos de investigación observacionales del Ministerio de Salud del Perú*(24)*, en la que, dada la naturaleza de las carreras, se realizaron la mayoría de las investigaciones, y que a la letra establece: “Al culminar o cancelarse el proyecto de investigación observacional, el investigador principal deberá presentar el Informe final a la Oficina General de Investigación y Transferencia Tecnológica”. En este sentido, se debiera ser más cuidadoso en el cumplimiento de estos requisitos que garantizarían la idoneidad y veracidad de los datos.

Este estudio nos deja una gran preocupación, ya que se establece que la toltalidad de los trabajos no cumple los criterios éticos establecidos en nuestra investigación, siempre bajo la premisa de que la ética no se puede cumplir parcialmente, sino que es un constructo de cumplimiento y respeto total, lo que categoriza y da valor a la investigación en las universidades, en donde los estudiantes de pregrado tiene una primera experiencia con el método científico y estas conductas pudieran orientarlos a las malas prácticas en investigación.

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COMPETENCIAS BIOÉTICAS EN LAS PRÁCTICAS HIDROTERAPÉUTICAS: PERSPECTIVAS DE EXPERTOS INTERNACIONALES

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Resumen: Objetivo: explorar las competencias bioéticas que terapeutas acuáticos consideran importantes para la práctica hidroterapéutica.
Metodología: cualitativa y fenomenológica, la muestra es intencionada y opinática, quedando constituida por 14 terapeutas acuáticos internacionales con más de 10 años de experiencia, quienes aceptan participar de una entrevista semi estructurada en modalidad *on-line*. Se realiza un análisis de contenido categorial temático utilizando el software Atlas Ti versión 23.
Resultados: se levanta una comprensión de las competencias bioéticas desde la corriente personalista, evidenciándose los siguientes componentes: sensibilidad bioética, conocimientos bioéticos, práctica bioética y relación bioética. Como categorías emergentes se encuentra la necesidad de formación acreditada, integridad académica, brechas de accesibilidad y una visión integral de salud.
Conclusiones: existen competencias bioéticas coherentes con la corriente personalista, el principio de vulnerabilidad y valores tales como el respeto, la humildad y la honradez, pero es necesario desarrollar otras relacionadas con el respeto, la responsabilidad e integridad. El desafío es consensuar las competencias bioéticas que, desde una mirada de salud integral, contribuyan a validar y regular la práctica acuática generalizada a nivel internacional.

Palabras clave: terapia acuática, hidroterapia, bioética, competencias, terapeutas

Bioethical Competencies in Hydrotherapy Practice: the view of international Aquatic Therapists

Abstract: Objectives: The main objective is to explore the bioethical competencies that aquatic therapists consider important in hydrotherapeutic practice at an international level.
Methodology: qualitative of a phenomenological type with an intentional and opinionated sampling. The sample is made up of 14 international senior aquatic therapists, who participate in semi-structured interviews in an online modality. Thematic categorical content analysis is carried out with the support of the Atlas Ti version 23 software.
Results: A comprehensive understanding of bioethical competencies is developed from a personalist perspective, highlighting the following components: bioethical sensitivity, bioethical knowledge, bioethical practice, and bioethical relationships. Emerging categories include the need for accredited training, academic integrity, accessibility gaps, and a holistic view of health.
Conclusions: The existence of bioethical competencies consistent with the personalist approach, the principle of vulnerability, and values such as respect, humility, and honesty is evident. This highlights the need to develop bioethical competencies related to respect, responsibility, and integrity. A challenge is posed to reach a consensus on bioethical competencies that, from a holistic health perspective, can contribute to the validation and regulation of widespread aquatic practice at an international level.

Keywords: aquatic therapy, hydrotherapy, bioethics, competencies, therapists

Competências bioéticas nas práticas hidroterapêuticas: perspectivas de especialistas internacionais

Resumo: Objetivo: explorar as competências bioéticas que terapeutas aquáticos consideram importantes para a prática hidroterapêutica.
Metodologia: qualitativa e fenomenológica, a amostra é intencional e opinativa, estando constituída por 14 terapeutas aquáticos internacionais com mais de 10 anos de experiência, que aceitaram participar de uma entrevista semi-estruturada na modalidade *online*. Realizou-se uma análise de conteúdo categorial temático utilizando o *software* Atlas Ti versão 23.
Resultados: se levanta uma compreensão das competências bioéticas de uma corrente personalista, evidenciando-se os seguintes componentes: sensibilidade bioética, conhecimentos bioéticos, prática bioética e relação bioética. Como categorias emergentes encontra-se la necesidade de formação acreditada, integridade acadêmica, lacunas de acessibilidade e uma visão integral de saúde.
Conclusões: existem competências bioéticas coerentes com a corrente personalista, o princípio de vulnerabilidade e valores tais como o respeito, a humildade e a honradez, porém é necessário desenvolver outras relacionadas com o respeito, a responsabilidade e integridade. O desafio é chegar a um consenso sobre as competências bioéticas que, desde uma perspectiva de saúde integral, contribuem para validar e regular a prática aquática generalizada a nível internacional.

Palavras-chave: terapia aquática, hidroterapia, bioética, competências, terapeutas

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Introducción

El concepto de "competencias" ha adquirido importancia a través del tiempo. La Organización para la Cooperación y el Desarrollo Económico (OCDE) comenzó a impulsar la Estrategia de Competencias para promover un enfoque estratégico de desarrollo que en su actualización considera tres componentes generales: a) desarrollar competencias necesarias a lo largo de la vida; b) usar las competencias de manera eficaz en el trabajo y en la sociedad y; c) fortalecer la gobernanza de los sistemas de competencias*(1)*.

Actualmente, la Organización de las Naciones Unidas para la Educación, la Ciencia y la Cultura (UNESCO) establece que el logro de competencias para el trabajo y la vida son cruciales para el crecimiento, productividad y la innovación inclusiva y sostenible, siendo uno de sus propósitos el apoyo y promoción de éstas. Considera que dichas competencias corresponden "a un conjunto de experiencias de aprendizajes relevantes para el mundo laboral y más allá de éste, que incluye el estudio de las tecnologías y las ciencias conexas, y la adquisición de competencias prácticas, actitudes, comprensión y conocimientos que ayudan a las personas a vivir vidas saludables y satisfactorias"*(2)*.

La OCDE señala que el desarrollo tecnológico y robótico, la inteligencia artificial generativa (IA) y los cambios medio ambientales requieren un fortalecimiento de los sistemas de educación inicial y las políticas en competencias, para garantizar la resiliencia como competencia clave en los procesos de transición verde y digital, y la capacidad de adaptación frente a desafíos en el curso de la vida, rescatando la importancia de la motivación para el uso de sus competencias en *pro* de la sociedad y la relevancia del sector político para ejercer un liderazgo ético y en equidad, para potenciar el bienestar social y económico*(3)*.

La Comisión Europea define "competencias éticas" como meta competencias profesionales, o competencias integradoras que implican una combinación de saberes teórico-prácticos y actitudinales relacionados a las funciones a desempeñar en contextos determinados, las cuales son esenciales para el desarrollo de la responsabilidad y la autonomía*(4)*. Corresponden a una serie de decisiones y acciones conscientes, actuando responsablemente en consideración de la normativa legal, consecuencias económicas, ecológicas y sociales*(5)*; contiene la capacidad de identificar problemas éticos, el conocimiento ético y moral, la auto reflexividad, la toma de decisiones acertadas y la gestión de situaciones éticamente desafiantes, siendo así la competencia esencial para el respeto de los derechos del paciente y la calidad de atención*(6)*. Ésta incluiría cualidades personales, como la justicia, humildad y preocupación por el bien común*(7)*. Las competencias éticas que se han descrito son: la sensibilidad ética, el conocimiento ético, la reflexión ética, la toma de decisión ética, la acción ética y el desarrollo ético*(8)*.

Uno de sus componentes es el uso de la sensibilidad para la promoción de un espacio que salvaguarde la vulnerabilidad individual, como también el aseguramiento de un clima de seguridad y confianza*(4)*, esta sensibilidad se ha descrito como la capacidad de reconocer áreas de tensión ética que pueden emerger de diversas situaciones, siendo una fuente de reflexión, toma de decisiones y una acción responsable, por lo tanto, constituye la pieza fundamental de la competencia ética en la práctica. Cabe destacar que podría estar relacionada con la compasión y con el desarrollo del conocimiento personal*(8)*.

Las competencias bioéticas corresponden a una serie de atributos personales para desarrollar acciones efectivas en ámbitos de desempeño*(9)*. En el contexto del presente estudio, corresponde a las competencias requeridas para el desarrollo de prácticas hidroterapéuticas a la luz de principios bioéticos.

Las prácticas hidroterapéuticas son definidas como la aplicación y uso del agua, sus principios, propiedades*(10)* y técnicas(*11)* para la salud y el bienestar*(12)* individual y/o colectivo. Algunos de los conceptos más utilizados para referirse a ellas son el trabajo corporal acuático (TCA) y la terapia acuática (TA). El impacto positivo de estas intervenciones se evidencia en diferentes sistemas corporales*(13-21)* y a nivel psicoemocional*(22-23)*, repercutiendo favorablemente en la calidad de vida y bienestar*(24-26)*. Algunos antecedentes constatan que las prácticas hidroterapéuticas se asocian con los principios del personalismo, como también al principio de vulnerabilidad, costo-beneficio y la presencia de valores característicos; sin embargo, se rescata la necesidad imperante de profundizar en las competencias bioéticas de las/os terapeutas*(27)*.

Si bien a nivel mundial se reconoce cada vez más la relevancia de las competencias bioéticas en cualquiera de las áreas del ejercicio profesional, existe escasa evidencia empírica en torno a las prácticas hidroterapéuticas, siendo altamente relevante explorar, desde la perspectiva de terapeutas acuáticos de nivel internacional, las competencias bioéticas requeridas para asumir adecuadamente estas prácticas.

Metodología

Diseño

Dado el carácter exploratorio del estudio, se emplea una metodología cualitativa que permite indagar la perspectiva de terapeutas acuáticos.

Participantes

La muestra se encuentra constituida por 14 hidroterapeutas internacionales (100%), 8 mujeres (57,1%) y 6 hombres (42,9%). Antecedentes laborales: 5 son profesionales de la salud dedicados a la TA (35,7%), uno es profesional del entrenamiento físico dedicada/o prioritariamente a la TA y excepcionalmente al TCA (7,1%), 4 profesionales de la salud que se dedican a la TA y al TCA (28,6%), un profesional de la salud que realiza exclusivamente TCA (7,1%), un profesional del entrenamiento que sólo realiza TCA (7,1%), una persona sin título profesional que se dedica al TCA (7,1%) y un terapeuta complementario que realiza TCA (7,1%).

País de procedencia: 5 chilenas/os (35,7%), 3 mexicanas/os (21,4%), 2 brasileñas/os (14,3%), un argentina/o (7,1%), un español/a (7,1%), un belga (7,1%) y un alemán (7,1%).

Muestra intencional y opinática, en la que los informantes clave reunían los siguientes criterios: a) más de 10 años de experiencia práctica profesional; b) habilitada/o por alguna organización, asociación, instituto o universidad para impartir docencia en técnicas o conceptos de hidroterapia; c) activa/o en la práctica y docencia hidroterapéutica; d) deseo voluntario de participar.

El grupo de terapeutas participó voluntariamente, con consentimiento informado.

Técnica de recolección de la información

Se utiliza una entrevista semiestructurada individual de tipo conversacional, para relevar las percepciones de los participantes, facilitando la compresión del significado del fenómeno desde la subjetividad personal.

La investigación abarca los hallazgos del eje temático competencias bioéticas requeridas en la práctica hidroterapeútica, en torno a la pregunta central "*¿Cuáles son las características, habilidades y/o competencias que debe tener una persona que se dedica a la TCA o TA?*".

Las entrevistas fueron realizadas por la investigadora principal, vía remota, por plataforma zoom, fluctuando entre 20 y 50 minutos; fueron grabadas en audio y luego transcritas a texto para posibilitar el análisis de contenido. Según el criterio de saturación teórica se interrumpen las entrevistas en el entrevistado 14.

Procedimiento para el análisis de los datos

Se realiza un análisis de contenido categorial temático de las relatorías levantadas en las entrevistas transcritas, utilizando el software Atlas Ti versión 23.

Resguardos bioéticos

La investigación respeta, mediante el uso de consentimiento informado, la autonomía de los participantes, brindando tiempo para plantear interrogantes, y asegura la confidencialidad al resguardar datos sensibles mediante codificación y cifrado. El acceso a los datos es exclusivo del equipo de investigadoras. El estudio ha sido aprobado por el comité de ética de la Universidad de Playa Ancha, Chile N° 15-2023.

Resultados

Del análisis de contenido, es posible apreciar que los conceptos que se levantan con una mayor frecuencia constituyen componentes competenciales del saber, saber hacer, saber ser y saber convivir, revelando la importancia de la adquisición de competencias bioéticas, en tanto actitudes, conocimientos, comportamientos y habilidades relacionales que sustenten el trabajo en terapia acuática, teniendo como eje el desarrollo de la persona (figura 1).

Figura 1: Nube de palabras del área competencias bioéticas de la práctica hidroterapéutica.

Los 10 conceptos principales son: tener/haber (539); ser (262); hacer /práctica/experiencia (264); medio acuático (223); poder/límites (203); estar (206); saber/conocimiento (185); decir/comunicación (168); ética/bioética (126); persona (123); trabajar (121).

Se identifican las siguientes categorías temáticas y emergentes:

Tabla 1: Categorías temáticas y subcategorías

Categorías	Subcategorías
Sensibilidad bioética	Apertura Evitar juicios Escucha activa Seguridad y confianza Privacidad, confidencialidad y autonomía
Conocimiento bioético	Filosófico/Deontológico Científico y del medio acuático Ético
Práctica bioética	Reflexión Métodos y técnicas
Relación bioética	Cuidado Distancia terapéutica Integración de Valores Trabajo en equipo interdisciplinar
Categorías emergentes	
Implicaciones educativas y socioculturales	Formación acreditada Integridad profesional Brechas en accesibilidad Visión integral de la salud

Fuente: elaboración propia.

Competencias bioéticas

1. Sensibilidad bioética

Desde la mirada de las/os participantes, la sensibilidad bioética implica una actitud de apertura sensorial y emocional, evitar juicios sin fundamentos, escucha activa y empatía, favoreciendo un clima de seguridad y confianza, atendiendo a las necesidades del otro y respetando los derechos de las personas a la privacidad, la confidencialidad y la autonomía, teniendo como eje el bienestar y la salud de la persona.

1.1. Apertura sensorial y emocional

"Siento que es una terapia que abarca toda la piel, todos los sentidos, es propioceptiva, requiere los 5 sentidos puestos, y también desde lo emocional; siento que toca esferas personales emocionales tan profundas de las personas, que siento que nosotros tenemos que tener esa percepción para poder captar esos elementos(…)" (E1).

"…conciencia corporal propia, conciencia corporal del otro al que damos la sesión y capacidad de establecer lo que llamamos diálogo tónico emocional, es decir ajustar nuestro trabajo según lo que está pasando, lo que sentimos, lo que la persona nos pidió y nos da como retroalimentación directa verbal o no verbal, entonces esas habilidades que son tanto de sentir como de hacer, son fundamentales" (E14).

1.2. Evitar Juicios

"…de repente nosotros estamos acostumbrados, en otras esferas a enjuiciar(…), no debemos caer en emitir juicios personales al respecto(…)" (E1).

"Ahora tú tienes grupos en los cuales hay un intercambio de realidades y de sexo, los que es más difícil(…), los principios de la terapia que nosotros realizamos son siempre 'bienvenido como eres' y 'muéstrate cómo eres', y eso es lo lindo que tiene, la transparencia del Ser, por eso yo creo que hoy en día tenemos que tener mucha más conciencia, más abierta con respecto a esos criterios y poner puntos de ética que son generales para todos, pero también con un límite(…)" (E4).

1.3. Escucha activa y empatía

"La capacidad de presencia y de escucha de las necesidades del paciente, no necesariamente lo que el paciente expresa verbalmente o los objetivos del paciente y de la familia, pero también qué está pasando en el cuerpo, la capacidad para escuchar más allá de las palabras, creo que son habilidades que más se tienen que desarrollar…" (E13).

"…ser empáticos en eso y saber escuchar, y te vas dando cuenta que el paciente te va dando solo las respuestas de lo que él quiere y lo que él necesita. A veces nosotros nos enfocamos en la kinesiología o en la terapia corporal, pero nos cerramos a lo que queremos nosotros y no escuchamos lo que realmente quiere la persona…" (E5).

1.4. Clima de seguridad y confianza

"Tiene que ser un profesional empático, cercano, que le guste trabajar con personas en este medio, que le guste trabajar en el agua, cosa de que se le haga agradable, tanto para el que va a recibir, como para que el que va a entregar, y desde el que va a entregar(…), tiene que haber sabido mostrar algún tipo de destreza en el agua para que pueda transmitir la confianza y seguridad de trabajar en este medio" (E12).

1.5. Privacidad, confidencialidad y autonomía

"…no decir nombre, siempre resguardar la identidad, o quizás la edad también, si es adolescente, adulto, adulto mayor (…). El paciente tiene derecho a elegir con quién se trata y dónde se trata…" (E1).

"…el entrenamiento es un entrenamiento terapéutico en el cual el participante participa voluntariamente, y que el participante puede parar el entrenamiento cuando él o ella quiere" (E2).

*"…es muy importante el consentimiento desde todo punto de vista para las distintas metodologías, herramientas, estrategias que uno vaya a usar como terapeuta…" (*E9).

2. Conocimiento bioético

Desde esta perspectiva, se espera que el terapeuta acuático cuente con conocimientos filosóficos/deontológicos, científicos, del medio acuático y éticos, como lo señalan los siguientes relatos:

2.1. Conocimientos filosóficos/deontológicos

"[…] código de ética y deontología […] más con relación a conceptos, a los métodos […]" (E6).

"Hay un código transversal que es el código del WABA, pero todos los institutos del mundo tienen la autorización de adaptarlo según las costumbres en el país. Allá hay adaptaciones muy leves" (E2).

2.2. Conocimiento científico y del medio acuático

"…de la mecánica de los fluidos, y de la fisiología, de la fisiología de la inmersión, aunado a la fisiología del ejercicio que se conoce en tierra, entonces, creo que muchos de estos conocimientos deben de tener una base muy sólida para poder realizar este análisis y razonamiento clínico, y que no se termine convirtiendo en una transposición de ejercicios dentro del agua o hacer ejercicios que se hacen en el medio terrestre en el medio acuático…" (E10).

"…tiene que ser competente en el manejo de las propiedades físicas del medio acuático, básicamente hablando de las leyes del movimiento de Newton, hablando de la ley de la dinámica de los fluidos y la resistencia acuática, hablando del principio de Arquímedes, hablando muchísimo de todo lo que tiene que ver con el análisis biomecánico en el medio acuático y el trabajo de cada uno de los grupos musculares y cadenas musculares, cómo se ve afectado por estar inmerso dentro del agua, eso para mí es como la base de la formación…" (E9).

2.3. Conocimiento ético

"…ética relacionada al trabajo, al relacionamiento, la intervención, (…) los principios éticos, tanto del trabajo como de uno mismo o lo que viene también con la filosofía de trabajo y lo que uno entrega. (…), la ética de preservar la capacidad de trabajo de uno y la intervención para el otro" (E8).

"…procesos desde consentimientos informados, que el paciente sepa lo que vas a trabajar, el tiempo que va a durar, y generar una retroalimentación etcétera, son las que pertenecen por ejemplo a; WABA: Watsu, y AquaHealing, (…) WastuPath… " (E11).

3. Práctica bioética

Actuar basado en la reflexión en torno a sus capacidades y límites; y flexibilidad en la utilización de métodos y técnicas que salvaguarden la persona, como lo señalan los siguientes relatos:

3.1. Reflexión en torno a capacidades y límites

"…creo que estaría primero su preparación, en este concepto entra mi condición básica para estar apto, una autoevaluación/autocrítica para ver si estás preparado para ejercicio físico dentro del agua" (E6).

"…siempre la pregunta fundamental es ¿a qué estamos sirviendo? ¿Estamos al servicio de quién? (…)" (E14).

"…tener muy claro, como profesional, los conceptos y la aplicación que va a usar, conociendo cuál es el motivo que acerca a esa persona al medio acuático (…) y cuáles serían los caminos alternativos para abordar esa prob*lemática por la cual se acerca; cuál es el límite en la incumbencia en base a lo que cada uno como profesional trae en su bagaje acuático (…), o sea, para mí eso es muy importante, esa línea, saber hasta dónde, de acuerdo a mi formación de base o a mis conocimientos, puedo éticamente abordar y tomar a cargo el tratamiento o el seguimiento… "* (E9).

"…conocer y respetar los límites de su trabajo, de sus propias competencias y referir a otro profesional si acaso lo que está surgiendo en una sesión no corresponde con el servicio que puede brindar" (E13).

3.2. Métodos y técnicas

"…el saber nadar es una práctica indispensable para una persona que va a dedicarse a la terapia acuática, ya sea horizontal o vertical, el tener algunas técnicas de dominio personal, como del fitness acuático, como algunas de las que ya están tipificadas como terapia acuática, como puede ser el WATSU (…) desde el punto de vista básico, salvamento o rescate acuático, natación, primero dominar los cuatro estilos, y si no los elementos de flotación (…), me parece relevante que el terapeuta sepa trabajar por su vida, su movimiento antes de tratar a una persona adicional en el medio acuático" (E11).

"…todos tendríamos, los que trabajamos en agua, tener el mínimo conocimiento básico de cómo hacer un RCP, por ejemplo, o cómo sacar a una persona que está con un problema en ese momento y de qué forma y cómo tratarla" (E3).

4. Relación bioética

El cuidado del yo, yo-otro vulnerable, distancia terapéutica basada en comunicación ética y disposición a vestir adecuadamente, anticipando el riesgo de relaciones duales, integración de valores que nutren y facilitan el trabajo en equipo interdisciplinar, elementos facilitadores de una relación terapéutica beneficiosa, como lo refieren los siguientes relatos:

4.1. El cuidado del yo, yo-otro vulnerable

"creo que, bioéticamente, son dos aspectos, el aspecto del cuidado con uno mismo y el aspecto del cuidado con el otro. Sí, en este campo el cuidado está incorporado a la vida de uno y del otro, lo que yo voy a hacer éticamente con el otro, con los conocimientos que yo tengo" (E8).

"…no tengo cómo separar la ética de la seguridad (…), seguridad para los dos lados, seguridad para el paciente y seguridad para el terapeuta; por ejemplo, estructurar los procedimientos, documentar (…), las atenciones son filmadas, registradas" (E6).

4.2. Distancia terapéutica

"…la comunicación en sí es un acercamiento respetuoso, en el cual yo tengo que respetar los límites de la otra persona, los límites del idioma, los límites

emocionales, los límites corporales, y responder a lo que la persona me pide. Y esos componentes de la comunicación ética son viceversa, ya que yo también tengo que de forma verbal como no verbal dejar claro cuáles son mis límites (…) para que el cliente tenga una experiencia terapéutica. Si no, se transforma en otra cosa” (E2).

“…estar dispuesto, como profesional, con una vestimenta adecuada, que mantenga dignidad, respeto, para evitar situaciones incómodas, ya que hay mucho toque, mucho contacto corporal, por eso es muy importante” (E6).

“es importante (…) el traje que uno use, el maquillaje, los olores, que sea obviamente una persona que no va a lucirse, sino que más bien va a acompañar un proceso muy delicado de otra persona y, por lo tanto, ahí el único protagonista es el agua y no la terapeuta, creo que trabajar el ego es algo muy importante” (E3).

4.3. Integración de valores

Respeto

“…es el respeto para mí la competencia más importante, no sé si es que hay la palabra correcta, el respeto a la profesión…” (E7).

“…yo siento que uno tiene que tener respeto al otro y respeto a sí mismo, respetarse uno, respetar al otro, y respetar la técnica” (E1).

Humildad

“Me tocó trabajar con las comunidades mapuches (…); me di cuenta que no sabía nada y eso fue maravilloso, entender que no sabía nada y que todavía lo pienso, no ¡sabemos nada! Realmente de todo lo que puede llegar a pasar o ser en una sesión de WATSU, la verdad que todos los días se aprende algo y eso también me apasiona porque no es una técnica que se cierra…” (E3).

*“…la búsqueda del crecimiento personal y profesional, o sea la necesidad de reciclarse, especialmente en terapia acuática porque es má*s emergente y hay más áreas *(…), y también tener la capacidad para derivar cuando algo se sale de nuestra área de competencia, tener humildad para poder derivar”* (E13).

Honradez

“…desde el primer acercamiento con la persona (…) el presentarse, el que tú eres tal persona, cuál es tu función o tu rol en el lugar de trabajo, explicar el procedimiento que se le va a realizar, que se mantenga claro cuáles son las ejecuciones que se van a realizar (…), entonces, todos esos factores que van un poco en el conjunto de educar y de generar un pronóstico, eso para mí ya empieza a ser ético en ese sentido…” (E5).

“…Tenemos que ser sinceros en la información que entregamos, no embaucar al paciente…” (E1).

4.4. Trabajo en equipo interdisciplinario

“La capacidad de trabajo en equipo, no solo con otros fisioterapeutas, sino con otros profesionales de la salud, ligado a esto de derivar, pero en sesión clínica también, como contemplar el trabajar juntos (…), entonces, esto me parece, aparte de ser una cualidad que es necesaria, es algo que se debe buscar” (E13).

“…ese trabajo interdisciplinario, en donde yo te aporte esto que nosotros vemos en el agua, más lo que vos sabés *de lo que es la rehabilitación, y en el acondicionamiento de una persona que se está readaptando en funcionalidad (…), ahí hacemos equipazos porque cada uno aporta desde su visión todos discutimos estrategias”* (E9).

5. Categorías emergentes

Desde la perspectiva de las/os expertas/os, a nivel educativo se plantea la necesidad de contar con una formación en terapia acuática acreditada mediante certificación, reflejando integridad profesional desde la docencia. A nivel sociocultural se observa brechas en accesibilidad, relacionado a costos de mantención, siendo una fuente de tensión ética en una sociedad que se compromete con la calidad en la salud, y también las dificultades en consensuar un código de ética que, desde una mirada de salud integral, contribuya a validar y regular la práctica hidroterapéutica a nivel internacional.

5.1. Implicaciones educativas y socioculturales

5.1.1. Formación en terapia acuática acreditada

"…unas cuantas horas de formación técnica por instructores (…), unas cuantas horas de prácticas libres con gente cercana no remuneradas, como sus prácticas para aprender a tocar otros cuerpos, con un profesor que dice lo que hay que hacer, supervisión individual para asesorar, nivelar, contestar preguntas, resolver dudas que hayan surgido en la práctica, unas cuantas sesiones de trabajo corporal para poder vivenciarlo desde el punto de vista del cliente-paciente y unas cuantas horas de formación fuera del agua que le den herramientas de trabajo físico, o de proceso emocional para acompañar la persona (…) en lo que pueda surgir al nivel de la sensación, de las emociones, del proceso terapéutico, de transformación o crecimiento personal, y una prueba final siendo el instructor que recibe una sesión del estudiante, que pueda evaluar, asesorar y certificar si es que tiene la cualidad requerida. Eso para mí serían los ingredientes imprescindibles en el recorrido de formación…" (E14).

"…la persona que está haciendo la terapia tiene que tener un entrenamiento de esta disciplina que es técnicamente adecuado, pero también pedagógicamente adecuado, porque dentro del trabajo corporal viene el trato de comunicación con el paciente, lo que se enseña en los cursos también, cómo se acerca al paciente antes de hacer el tratamiento, y también cómo se hace el feedback *después de la sesión, y cómo se responde durante el desarrollo de la sesión al cliente (…); esas son habilidades pedagógicas y habilidades de acompañamiento"* (E2).

"Éticamente hablando, por supuesto que tener una formación ad hoc *que te acredite (…), que de alguna manera lo certifique(…), y que obviamente tenga experiencia… "* (E3).

5.1.2. Integridad profesional

"…es fundamental que los profesores sean un ejemplo con respecto a la ética (…), yo voy más a la práctica, a que si realmente se cumple, porque si no, no tiene ningún sentido que tu pongas, hagas un tremendo manuscrito y que después esas cosas no sean factibles de cumplir" (E4).

5.1.3. Brechas de accesibilidad

"…la fisioterapia acuática tiene una gran desventaja (…), necesita de una piscina y una piscina con agua caliente y que no es barato, no hay mucho... pocas personas que pueden tener un espacio, mantener un espacio así, entonces, la fisioterapia acuática es también cara para muchas personas y los convenios de salud no quieren pagar la fisioterapia acuática porque no reconocen que es un tratamiento efectivo, entonces mucha gente tiene que poner plata de su bolsillo, para hacer el trabajo" (E8).

5.1.4. Visión integral de salud

"La medicina tradicional ortodoxa y la medicina ancestral (…) empiezan a acercarse y quizá eso va a generar una mirada más amplia de lo que significa la salud integral, y tomarse de la mano y generar ahí un vínculo maravilloso para poder también trascender (…), y quizás ahí, cuando logremos como entablar esa relación sin oposición, donde de alguna manera haya un tema de aceptación del uno hacia el otro, se pudiera generar un código de ética que no discrimine" (E3).

Discusión

Respecto de las competencias bioéticas de la práctica hidroterapética, las reflexiones de los expertos permiten relacionarlas con principios del personalismo, tal como sucedió en un estudio previo*(27)*, siendo coherente con la frecuencia de palabras obtenida, ya que el concepto de "persona" resulta ser prioritario en comparación con "paciente", "usuario" o "cliente". A continuación, se describe la vinculación hallada entre principios y categorías analizadas.

El *principio de defensa de la vida física* se manifiesta en las narraciones de las/os hidroterapeutas al aludir a conocimientos deontológicos, científicos y del medio acuático y ético para la realización de procesos de intervención adecuados, además, desde un punto de vista deontológico, los profesionales de la salud declaran en su código de ética la beneficencia y no maleficencia acorde a la declaración de Helsinki*(28)*; ambos principios del principialismo se relacionan íntimamente con la defensa de la vida física. Los procesos de autoevaluación y reflexión en torno a capacidades y límites, así como en los métodos y técnicas utilizados pretenden salvaguardar la vida de la persona durante la *praxis*; y la formación acreditada sería la garante de la adquisición de competencias teóricas, técnicas, procedimentales y actitudinales relacionados con una atención idónea en el medio acuático.

El *principio de libertad-responsabilidad* se observa en la sensibilidad bioética al resguardar la privacidad, confidencialidad y autonomía de la persona, además en el conocimiento bioético y práctica bioética se visualiza en las narraciones la obligación de salvaguardar la vida y el cuidado de la salud (propia y de los demás)*(29)*, relevando la necesidad de conocimientos teóricos y prácticos como base de los procesos de intervención, correspondiendo a una garante de éstos la realización de procesos formativos acreditados.

El *principio de totalidad* se encuentra asociado a los conocimientos, la práctica y a la escucha activa considerando a la persona como un todo, tanto bajo la comprensión de los efectos corporales y psicoemocionales, como de los desafíos relacionados con la práctica integrada con otros profesionales o adquiriendo conocimientos de otras culturas, generando una visión integral de la salud. Este principio también se relaciona con no falsear información, no generar falsas expectativas del proceso de intervención, acorde a Sgreccia*(30)*.

El *principio de sociabilidad y subsidiariedad* se evidencia en la sensibilidad ética, considerando la relación de apertura requerida, evitar los juicios personales y mantener una escucha activa que se traduzca en un ambiente de confianza y seguridad para la persona. La generación de este clima terapéutico implica una comunicación clara y fluida en pro del beneficio de la/s persona/s, como también en el logro de un trabajo en equipo interdisciplinario en el medio acuático, permitiendo un abordaje integral. Finalmente, se visualizan las brechas existentes en accesibilidad, evidenciando que aún se requiere aumentar los esfuerzos para hacer que este tipo de intervención pueda ser utilizada de forma colectiva, mejorando de esta manera las garantías sociales existentes para el cuidado de la vida y de la salud, coherentemente con las bases conceptuales del principio aludido*(29-30)*.

Es posible apreciar que las competencias bioéticas en la práctica hidroterapéutica implican un conjunto de valores que las/os participantes destacan, como el respeto, la humildad y la honradez. Estos resultados son coherentes con los valores hallados en estudio previo*(27)*, como también por lo declarado por deontologías profesionales*(31)*, estudios disciplinares*(32-33)* y del TCA*(34)*. Es importante agregar que el principio de vulnerabilidad (no perteneciente al personalismo) se refleja en el cuidado, la distancia terapéutica (relación bioética) y en la seguridad y confianza (sensibilidad bioética), asociándose con la dignidad humana y su protección*(35)*.

En consideración de lo anterior es que resulta menester continuar profundizando en la temática, contrastar las percepciones entre las diferentes modalidades hidroterapéuticas, generar instrumentos para recopilar antecedentes en torno a las diversas realidades y, de esta forma, generar una contribución a los procesos formativos y socioculturales que permitan avanzar desde una mirada de salud integral para todas y todos, con implicaciones para la implementación de políticas públicas.

Conflicto de intereses: No se declaran conflictos de interés.

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ESPIRITUALIDAD DE PROFESIONALES DE LA SALUD EN UNIDADES DE PACIENTES CRÍTICOS EN CHILE DURANTE EL COVID-19

Verónica Guerra Guerrero[1], Marcelo Correa Schnake[2], Margarita Poblete Troncoso[3], Andrea Páez[4], María Carolina Daneck Muñoz[5]

Resumen: La pandemia tuvo consecuencias multidimensionales. Los profesionales de la salud fueron afectados debido a situaciones estresantes y traumáticas a lo largo del tiempo. El objetivo es analizar la espiritualidad como uno de los temas principales derivados de las experiencias vividas por un grupo de profesionales de la salud en unidades de pacientes críticos durante la pandemia. Se trata de un estudio con enfoque fenomenológico hermenéutico, con entrevistas en profundidad a 30 profesionales de la salud en Chile. El análisis de datos fue de tipo temático y se mantuvo los resguardos éticos correspondientes. Se encontró que la espiritualidad se relaciona con la reflexión y creencias espirituales del equipo de salud, y que la espiritualidad se redescubre a partir de la experiencia profesional y personal deshumanizadora a la que conduce la pandemia.

Palabras clave: espiritualidad, profesionales de la salud, covid-19, experiencias de vida

Spirituality of health professionals in critical care units in Chile during covid-19

Abstract: The pandemic had multidimensional consequences. Healthcare professionals were affected due to stressful and traumatic situations over time. The objective is to analyze spirituality as one of the main themes derived from the experiences lived by a group of health professionals in critical patient units during the pandemic. This is a study with a hermeneutical phenomenological approach, with in-depth interviews with 30 health professionals in Chile. The data analysis was thematic and the corresponding ethical safeguards were maintained. It was found that spirituality is related to the reflection and spiritual beliefs of the health team, and that spirituality is rediscovered from the dehumanizing professional and personal experience to which the pandemic leads.

Key words: spirituality, healthcare professionals, covid-19, life's experiences

Espiritualidad de profesionales de la salud en unidades de pacientes críticos en Chile durante el covid-19

Resumo: A pandemia teve consequências multidimensionais. Os profissionais de saúde foram afetados por situações estressantes e traumáticas ao longo do tempo. O objetivo é analisar a espiritualidade como um dos principais temas decorrentes das experiências vividas por um grupo de profissionais da saúde em unidades de terapia intensiva durante a pandemia. Este estudo utiliza uma abordagem fenomenológica hermenêutica, com entrevistas em profundidade com 30 profissionais da saúde no Chile. A análise de dados foi de tipo temático e foram mantidas as salvaguardas éticas correspondentes. Constatou-se que a espiritualidade está relacionada à reflexão e às crenças espirituais da equipe de saúde, e que a espiritualidade é redescoberta por meio das experiências profissionais e pessoais deshumanizantes causadas pela pandemia.

Palavras-chave: espiritualidade, profissionais da saúde, covid-19, experiências de vida

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Introducción

La pandemia mundial del covid-19, que llevo a un confinamiento y reducción del contacto físico con otros, implicó importantes cambios a nivel personal, social y económico en la población*(1)*. En Chile, según el Ministerio de Salud, desde el inicio de la pandemia se registran 5.289.677 casos confirmados acumulados y 52.709 fallecidos confirmados totales*(2)*.

A nivel personal, la pandemia ha tenido consecuencias en los aspectos físicos, psicológicos y espirituales. Ante este cuadro, los profesionales de la salud son uno de los grupos de mayor vulnerabilidad, debido a que tienen un alto riesgo de infectarse, sufrir problemas físicos, psicológicos y emocionales al estar en la primera línea, proporcionando cuidados a todos los pacientes que se contagian. Se adiciona el hecho de sentir miedo y angustia de contagiar el virus a su familia, llevando a muchos de ellos a separarse de sus seres queridos para evitarlo*(3)*. El equipo de salud estuvo arriesgando su propia vida para salvar a las personas que tenían la enfermedad, al mismo tiempo que tuvieron que entregar cuidado compasivo*(4)*.

Por tanto, el equipo de salud no solo se encuentra expuesto al contagio del virus, sino que también a una sobrecarga emocional sostenida en el tiempo, por vivencias de situaciones estresantes y traumáticas; aun cuando se trata de una población entrenada y dedicada a la atención de situaciones extremas, ello no los vuelve inmune al sufrimiento humano*(5,6)*.

Además, para el personal sanitario, la pandemia ha significado un enorme compromiso ético en la atención de salud, ya que se ven expuestos en muchos casos a escenarios críticos, siendo una de estos la experiencia de duelo por la muerte de los pacientes*(7)*. Estas experiencias generan emociones intensas, lo que lleva a experimentar cambios profesionales y espirituales profundos*(8)*.

Respecto de esto último, según la Association of American Medical Colleges (1999), la espiritualidad puede ser definida como "un factor que contribuye a la salud de muchas personas. El concepto de espiritualidad se encuentra en todas las culturas y sociedades. Se expresa en la búsqueda individual de un significado último, a través de la participación en la religión y/o la creencia en Dios, la familia, el naturalismo, el racionalismo, el humanismo y las artes. Todos estos factores pueden influir en cómo los pacientes y los profesionales de la salud perciben la salud y la enfermedad y cómo interactúan entre sí"*(9)*.

Esta definición de la espiritualidad, la sitúa en interacción con la religión institucional, pero sin jamás identificar los dos conceptos*(10)*. Es así como algunos autores describen, por ejemplo, una espiritualidad "laica" o "inmanente"*(11,12)*, es decir, sin vínculo con la dimensión propiamente religiosa y confesional. En este sentido, la espiritualidad va más allá de la religión, inscribiéndose más bien en la estructura antropológica del sujeto humano, bajo la forma de una apertura a la dimensión de trascendencia, que permite al sujeto encontrar, formular y expresar una "significación última" a su vida*(13)*.

Por su parte, la autotrascendencia es considerada un factor clave en el desarrollo humano y en la creación de significado, siendo ampliamente usada en la filosofía y psicología para referirse a una serie de conceptos y fenómenos relacionados*(14)*.

Según lo anterior, en las múltiples situaciones de vulnerabilidad a las que está expuesto el personal de salud, la movilización de la dimensión espiritual puede contribuir a la construcción de estrategias para ayudar a los pacientes, familias y cuidadores, contribuyendo así a una mejor integración del sufrimiento*(15,16)*.

Estas dos dimensiones del ser humano, la espiritualidad y vulnerabilidad, conforman una unidad que permite y proyecta la vida. El origen relacional del ser humano implica una dinámica de vida en la que los cambios son parte constitutiva del desarrollo. En este sentido, las crisis, los quiebres, los sufrimientos y las pérdidas no son expresión del sin sentido de la existencia, sino expresiones de una dinámica de humanización, en la que el desapego y la donación son las claves para constituirnos en seres más humanos ante la pérdida y el duelo.

Los profesionales de la salud están incluidos dentro de los grupos vulnerables afectados por la pandemia. El aislamiento social que implica estar alejado de la familia, el miedo a contraer la enfermedad y los aspectos éticos que implica el uso de recursos inadecuados o limitados, presenciar muertes masivas de pacientes y sobrecarga laboral, los expone al estrés y burnout*(17-19)*.

Acerca de los efectos de la pandemia en la dimensión psicosocial, algunos autores*(20)* mencionan que la espiritualidad está dentro de los factores protectores para manejar la ansiedad y el estrés ocasionados por la pandemia. Otros describen que la pandemia aumentó la necesidad de cuidado espiritual en los pacientes, familia y en los propios profesionales de la salud, como lo señalan estudios realizados en Italia y Sudáfrica, donde los médicos acompañaron a los pacientes en su etapa final, incluso realizando actos rituales, lo que muestra la importancia de la capacitación de los equipos de salud en la entrega de apoyo espiritual*(21,22)*.

Por esta razón, se ha propuesto realizar programas de cuidado espiritual para los profesionales de la salud, quienes trabajan en primera línea, especialmente en hospitales y residencias sanitarias*(4)*. Al respecto, se describe que el rol de la fe y del cuidado espiritual para el equipo de salud es imperativo y debería ser ofrecido activamente por equipos especializados en este tipo de cuidados, definidos como multi religiosos/no religiosos, de capellanía/cuidado espiritual*(4)*.

Algunos estudios muestran la importancia de la espiritualidad en el cuidado en salud, ya que da estabilidad y significado a las personas. Sobre esto, ya desde 2001 se describe la importancia de la espiritualidad frente a la muerte, para el afrontamiento y la recuperación en los cuidados que se otorgan en salud*(23)*, puesto que el cuidado espiritual o compasivo involucra servir a la persona en su totalidad: física, emocional, social y espiritualmente.

La espiritualidad es un recurso fundamental en situaciones de desastres como la pandemia*(24)*, la que, sumada a la religiosidad, se convierte en un importante mecanismo de afrontamiento para superar los problemas de salud física y mental, y promover las emociones que podrían fortalecer el sistema inmune y reducir el sufrimiento.

Otros estudios describen beneficios de la espiritualidad en relación con la mortalidad, afrontamiento y recuperación frente a la enfermedad*(9)*. Se ha demostrado que las personas que tienen prácticas espirituales regulares viven más tiempo; quienes tienen compromiso religioso pueden mejorar el control del estrés, al ofrecer mejores mecanismos de afrontamiento, mayor apoyo social y el fortalecimiento de los valores personales y de la visión del mundo. Asimismo, las personas con mayor espiritualidad pueden utilizar sus creencias para afrontar la enfermedad, el dolor y estrés, y tienden a tener mejor actitud y calidad de vida, tal como ha sido descrito por la Organización Mundial de la Salud*(25)*.

De acuerdo con lo anterior, en 2022 se llevó a cabo una investigación en los equipos de salud de las unidades de pacientes críticos en hospitales de alta complejidad en la región del Maule, Chile, con el objetivo de conocer las experiencias de duelo que presentaron dichos equipos durante la pandemia, desde la mirada de la vulnerabilidad, espiritualidad y auto transcendencia del ser humano. Se buscó analizar en profundidad la espiritualidad derivada de las experiencias vividas por un grupo de profesionales de la salud en unidades de Paciente Crítico durante la pandemia.

Metodología

Este artículo describe el análisis de los resultados de la investigación realizada en equipos de salud de las unidades de pacientes críticos en tres hospitales de alta complejidad en la Región del Maule, Chile. El objetivo de dicha investigación fue conocer las experiencias de duelo que presentaron los equipos durante la pandemia, desde la mirada de la vulnerabilidad, la espiritualidad y la auto transcendencia del ser humano.

El enfoque utilizado en dicho estudio fue fenomenológico hermenéutico, siendo el que también guio la reflexión y análisis en profundidad del tema de “espiritualidad” que se aborda en este artículo. Se destaca que la investigación se llevó a cabo con personal de salud (médicos, enfermeros, kinesiólogos y técnicos de enfermería) que trabajaban en unidades críticas, utilizando un muestreo no probabilístico por conveniencia, logrando incluir a 30 participantes.

Los resultados obtenidos derivaron del análisis de las entrevistas individuales en profundidad, que incluyeron preguntas del tipo: ¿Cómo ha sido su experiencia de duelo, como integrante del equipo de salud, a causa del *covid-19?* ¿Se produjeron cambios (anímicos, morales, éticos, *prácticos, espirituales) en el equipo de salud a consecuencia de las muertes por covid-19?*

El análisis de datos fue de tipo temático acorde a Van Manen, cuyo objetivo es transformar la experiencia vivida en una expresión textual de su esencia. La investigación contó con la aprobación del Comité de Ética Científico de la Universidad Católica del Maule Acta N°72/2021, y con las autorizaciones sanitarias correspondientes.

Resultados

Las entrevistas fueron realizadas a ocho enfermeras, nueve técnicos de enfermería, ocho kinesiólogos y cinco médicos. La experiencia laboral que tenían iba de 2 a 18 años; siendo la mayoría de los participantes mujeres.

En el análisis de esta investigación se identificó seis temas principales, tal como se describe en la tabla 1, identificándose la "espiritualidad" como uno de los temas principales que emergieron de las experiencias significativas y compartidas por el equipo de salud ante la vivencia del duelo en tiempos de pandemia. En este tema emergieron como subtemas: reflexiones espirituales, creencias espirituales y prácticas espirituales.

Tabla 1. Análisis temático

Tema	Subtema
Familia	Familia propia Familia de los pacientes
Muerte en pandemia	Rituales de la muerte Soledad de la muerte Mecanización de la muerte
Emociones y sentimientos	Miedo Pena Frustración
Afrontamiento	Deshumanización Autocuidado
Condiciones laborales	Salud mental y física Trabajo desgastante Abandono del sistema
Espiritualidad	Reflexión espiritual Creencias espirituales Prácticas espirituales

De acuerdo con lo anterior, a continuación se presentan los subtemas correspondientes al tema "espiritualidad".

Subtema 1: Reflexiones espirituales.

Los participantes señalaron que, posterior a la pandemia, hubo un cambio de perspectiva en relación con el sentido de la vida, en el que la espiritualidad adquirió mayor relevancia, como lo señaló el siguiente participante:

"Yo creo que hubo cambios de todo tipo, yo creo que uno mismo se puso más espiritual, más 'pensar en el momento', si tenemos un fallecido dedicarle un poco más de tiempo, incluso decir una oración" (entrevista 6, líneas 88-91).

Los participantes reconocieron que la espiritualidad se vivió de forma personal, de acuerdo con la creencia de cada uno:

"El apoyo espiritual lo ve cada uno en la medida de sus creencias, más que nada, cada uno tiene su propia creencia" (entrevista 6, líneas 99-100).

Vivir esta experiencia de crisis sanitaria hizo que los profesionales de la salud se cuestionaran sus propias creencias y apoyaran a los enfermos que fallecían en soledad a través de su compañía:

"Me he cuestionado algunas cosas y decía: "no puede ser así, no tiene que ser así, tiene que ser de otra forma, tienen que sentir que estábamos ahí, que si bien se intentó todo también estamos preocupados de que el paso hacia la otra vida sea una bonita experiencia a pesar de estar ahí en el ámbito hospitalario" (entrevista 3, líneas 149-155).

La siguiente reflexión señala la importancia de la vida del paciente por sobre su propia vida, en el cual la vocación de profesional de la salud pasa a tener un valor trascendente:

"Creo que uno puso su vida y por encima la vocación de servicio, a nosotros nos importaba más la vida del paciente que la nuestra y creo que la empatía y la vocación de servicio, el trabajo en equipo, el cuidarse uno al otro dentro del grupo" (entrevista 2, líneas 270-274).

Subtema 2: Creencias espirituales

Las creencias espirituales se relacionan con la fe, la religión y la búsqueda de una conexión con algo más allá de lo material y tangible. Para muchas personas, las creencias espirituales se constituyeron en una fuente de consuelo y fortaleza en momentos difíciles, como se puede notar en el siguiente relato:

“El creer en Dios y estar en oración, creer en él, la fe, la propia fe. Yo, como católico, me aferro a eso” (entrevista 19, líneas 66-68).

Por otro lado, tener una creencia espiritual dio herramientas a los participantes para acompañar a otras personas en los momentos difíciles:

“Así como creo en Dios, creo también en las energías universales, así que me voy a eso, a que su camino, el camino al que va a emprender, sea un camino lleno de luz, darle apoyo a la familia” (entrevista 28, líneas 102-105).

La pandemia ha llevado a algunos participantes a reflexionar sobre la vida y la muerte y a preguntarse cuál es el propósito de la existencia:

“Sí, creo que a mis casi 33 años conocí religiones… estamos de paso por esta vida y venimos a cumplir ciertos objetivos y cuando ya los cumplimos o a veces no se llegan a cumplir pasamos a otro estado en el cual volvemos, quizás a este mismo plano terrenal en otra vida, en otra cosa, en un ave, en un árbol o quizás nuevamente también encarnado en una persona, pero lo que yo veo es que somos seres más allá del plano carnal, somos seres más celestiales, más astrales y viajamos, viajamos siempre; quizás estamos aquí ahora y en la otra vida estuvimos en otra situación, en otro momento. Así lo veo yo, entonces eso me ha ayudado también para afrontarlo” (entrevista 3, líneas 159-173).

Los participantes manifestaron su creencia espiritual como parte de su cotidianidad laboral, lo que dio sentido al trabajo que tuvieron durante la pandemia:

“Yo creo que solo amar la profesión, amar lo que hacemos y amar al prójimo” (entrevista 2, líneas 277-278).

Subtema 3: Prácticas espirituales.

Las reflexiones y creencias del personal de salud se tradujeron en algunas prácticas espirituales que ayudaron a dar sentido a los momentos en que moría un paciente. La práctica más mencionada fue la oración, seguida de la conversación y guardar silencio.

La práctica de la oración fue lo que se señaló con más frecuencia, especialmente ante lo inminente de la muerte de un paciente y se constituyó en una práctica común entre el personal.

“Rezábamos bastante, cuando ya sabíamos que iba a fallecer, hay muchos compañeros que rezan, lo hacíamos muy seguido” (entrevista19, líneas 79-81).

En algunos casos, esa oración se vinculaba con una práctica más afectiva del cuidado, relacionando esta práctica con una muerte sin dolor:

“Cuando uno ya ve que es inherente (*inminente*) la partida de un paciente, al menos en mi caso, yo les rezo, les doy sus últimas atenciones con más amor de lo habitual, en tanto que sus últimos momentos sean sin dolor” (entrevista 28, líneas 84-88).

Se evidenció también que la práctica de la oración estaba motivada por distintas creencias. No se rezaba solo a un ser trascendente que pudiera escuchar, sino que se rezaba también al universo solicitando su energía para enfrentar esos momentos.

“Soy creyente, le pido a Dios por el descanso del paciente, le pido al universo también porque creo, así como creo en Dios, creo también en las energías universales” (entrevista 28, líneas 100-103).

Otra forma de practicar la espiritualidad fue a través de la conversación en torno a la muerte de los pacientes. Si bien no se especifican los contenidos de esas conversaciones, sí se señala con quienes las realizaban. Lo más frecuente era con los compañeros de trabajo, con la pareja u otro familiar, y con algún agente religioso, como un sacerdote.

El equipo de salud dialogaba acerca de cómo les afectaba esta situación en el ámbito personal, familiar y laboral. Por ejemplo, se señala que a partir de estas conversaciones desarrollaron mecanismos de defensa para enfrentar el difícil escenario que estaban viviendo. "Conversábamos en el equipo lo que estábamos viviendo como persona y en nuestra familia, y como estábamos enfrentando esta situación. Yo creo que eso nos ayudó a enriquecernos como persona, nos ayudó a lo mejor a buscar nuevos mecanismos de defensa para poder fortalecer un poquito nuestro espíritu" (entrevista 17, líneas 155-158).

Algunas personas del equipo de salud, según las confesiones religiosas que profesaban, buscaban apoyo y orientación en sus pastores. Éstos, al visitar el hospital, eran abordados por el personal para conversar y recibir consejos que les permitieran continuar con sus vidas y funciones.

"También los fines de semana, cuando hace visitas algún monseñor o cualquier otra persona, trato de conversar, aunque sea cinco minutos con él para recibir algún tipo de consejo y poder seguir, porque la fe es súper importante para los que somos creyentes" (entrevista 19, líneas 68-73).

Otras prácticas espirituales que se reconocen en las entrevistas se refieren a la meditación y al silencio. Se señala la necesidad de detener la actividad cotidiana para dejar espacio a la reflexión y al silencio, reconociendo lo útiles que son para crear un ambiente que aporta sentido al momento de la partida de un enfermo. Así lo expresa uno de los entrevistados:

"Una cosa así, que ayuda en el momento, o detenerte a pensar o dar un momento de silencio, cosas así, que no fuera todo tan frío más que nada" (entrevista 6, líneas 91-92).

Discusión

La fragilidad experimentada por el personal de salud en las unidades de cuidados intensivos durante la pandemia los llevó a redescubrir en su propia humanidad la fuerza que los anima y da sentido a sus vidas, lo que es definido por algunos autores como la "dimensión espiritual", que se relaciona con las creencias religiosas, las que conectan la vida presente con un futuro trascendente, que reconocen en la muerte el paso a otra vida e identifican esa fuerza animadora con una deidad o con una energía universal que da sentido.

La espiritualidad se vive como un viaje hacia la interioridad, con la meditación u otras formas más centradas en la experiencia interior. También se puede vivir de forma intelectual, a través del estudio y la lectura de libros, así como para otros puede estar más enfocada en acciones y organizaciones, al ayudar a otras personas o contribuir al mejoramiento del mundo*(26)*.

Por su parte, el concepto integral del hombre supone que éste no es tan solo un ser bio-psico-social, sino también espiritual y religioso*(27)*, por lo tanto, comprender la enfermedad implica comprender a la persona enferma, y comprenderla implica, a su vez, aprehender todas sus dimensiones (física, psicológica, social y espiritual)*(28)*.

La espiritualidad en los entornos sanitarios, durante la pandemia del covid-19, se presentó como un reto para los profesionales de la salud y los pacientes*(29)*, ya que fue llevada al extremo, interpelando al ser humano como parte inherente y esencial. Por esto, algunos autores*(28)* mencionan que la atención sanitaria debe incorporar la dimensión espiritual, comprendiéndose como la fuente de capacidades del ser humano para afrontar la vida y la enfermedad.

Para los profesionales de la salud de esta investigación, la pandemia significó tener que cuidar la espiritualidad propia y del otro*(30)*, en orden a encontrar el propósito y aprendizaje de lo vivido, es decir, buscar un sentido a la experiencia vivida, en un momento de caos e incertidumbre.

Desde diferentes disciplinas, la espiritualidad es presentada como una dimensión del ser humano, que se desarrolla durante toda la vida, en la medida que atiende a las preguntas sobre el sentido y significado último de la existencia, en relación consigo mismo, con los otros, con el entorno o con la deidad*(31)*, cuestión que el personal de salud entrevistado comprendió al reflexionar sobre las frustrantes y cuestionadoras experiencias vividas durante la pandemia. Tal como lo plantean otros autores*(32)*, estas vivencias extremas permitieron a los profesionales comprender la espiritualidad como parte del ser humano, viendo a las personas y hechos desde una nueva perspectiva;

reflexionar acerca de cuestiones esenciales y existenciales de la vida, y reconocer de forma ética las creencias y valores de las personas que atendían.

En los relatos de los participantes de este estudio es posible comprender cómo vivieron su espiritualidad en la pandemia, en la que fueron experimentando cambios en sus formas de pensar la vida, dando en esta reflexión significado a su vida ya sea descubriendo y disfrutando de la naturaleza o estando cerca de las personas queridas. En segundo lugar, las experiencias se vincularon con las creencias espirituales, logrando consuelo y fortaleza y generando estrategias para acompañar a otros. En tercer lugar, éstas también se relacionaron con las prácticas espirituales de los participantes, tales como la oración, conversación y el silencio.

Por lo tanto, la espiritualidad implica la búsqueda de un significado en nuestras vidas, siendo una interconexión con uno mismo y los demás, y ofreciéndonos un camino continuo de descubrimiento*(33)*. Así, la espiritualidad puede ser entendida entonces como una búsqueda personal a través de la reflexión, para comprender el sentido de la vida, la relación con lo sagrado y con el final de la vida terrenal, y que puede o no llevar a la realización de prácticas religiosas*(34)*.

La muerte de los pacientes hizo que el equipo de salud repensará sobre su vida y la de sus seres queridos, y que vieran reflejada su propia vulnerabilidad, cambiando su forma de ver la vida y de cuestionarse acerca de su significado. La espiritualidad aparece en casos extremos de sufrimiento, cuando se expresa la necesidad del alma-espíritu que trasciende lo corpóreo, lo que lleva a reconocer en sí mismo y en el otro la vivencia espiritual*(35)*.

La importancia del autocuidado en el personal de salud durante la pandemia, y el cómo vivir la espiritualidad a través de la reflexión, contemplación y autotrascendencia, pueden convertirse en acciones para este autocuidado*(30)*, que es lo que fue planteado por los participantes de este estudio.

Mediante las creencias y prácticas espirituales las personas lograron afrontar y cuidarse de las situaciones complejas que vivieron por la pandemia, lo que también es reconocido como estrategias resilientes que facilitan el autocuidado*(30)*, destacándose la reflexión espiritual como una forma de lograr el equilibrio entre mente, cuerpo y espíritu, y también como una forma de ver la vida cuando se buscan respuestas más allá del plano terrenal. La dimensión espiritual consiste en una búsqueda para comprender el sentido de vivir frente a la finitud que tiene la vida*(36)*. Entender la espiritualidad como parte del ser humano es ver a las personas y hechos desde una nueva perspectiva; es reflexionar sobre cuestiones esenciales y existenciales de la vida, reconocer de forma ética las creencias y valores en las personas en salud*(37)*.

La espiritualidad se puede entender como una dimensión del ser humano, que se desarrolla durante toda la vida, en la medida que comprende el sentido y significado de la existencia consigo mismo, los otros o la deidad. En este sentido, las experiencias del personal de salud fueron consideradas desde esta perspectiva.

Además, se encontró que la espiritualidad está vinculada a las propias comprensiones de humanidad que los participantes manifestaron, y no como una realidad externa al ser humano que deben atender de modo diferenciado según su profesión y vida personal. En tal sentido, se observa en los distintos entrevistados que la pandemia por covid-19 los llevó a cuestionarse profundamente su espiritualidad, su encuentro consigo mismo y con los otros. La espiritualidad aparece también vinculada a las relaciones que se establecen con las familias de los pacientes y las propias. Estas son consideradas por los entrevistados como fuentes de sentido y estímulo para seguir adelante.

Por otra parte, los participantes también describieron que no podían contar con el apoyo de agentes religiosos (sacerdotes, pastores y laicos), con quienes tradicionalmente se vincula la espiritualidad, al concebirla en su dimensión religiosa. Por tanto, ya no se impartían sacramentos ni se hacían oraciones de sanación u otras prácticas, por lo que el mismo personal tuvo que realizarlas y asumirlas en ausencia de agentes religiosos. Los entrevistados refirieron que esta imposibilidad de rezar con los pacientes les afectaba mucho, principalmente porque veían que la ausencia de ritos los despojaba de la dignidad de la persona. Respecto de los rituales espirituales, un estudio*(38)* encontró que estos fueron limitados debido al aislamiento y restricciones sanitarias, imposibilitando el uso de estampas, objetos personales y ritos de las familias frente a la muerte.

La religión es considerada un sistema de creencias, prácticas, rituales que facilitan el acceso a lo sagrado, vinculado a una institución, con características doctrinales similares y específicas compartidas por un grupo, pero practicado individualmente*(34)*. La religión, en el caso de los profesionales de la salud durante la pandemia, fue considerada como una práctica para afrontar el duelo que vivían en la muerte de los pacientes, lo cual también ha sido descrito como una dimensión que debe ser considerada en la asistencia en unidades de cuidados intensivos. En este sentido, se describe que la participación de las personas en la religión está asociada positivamente con factores subjetivos, como la felicidad, el afecto, la alta moralidad y la satisfacción con la vida*(39)*.

Al respecto, es importante destacar que la espiritualidad se considera como un aspecto más amplio que la religión, siendo relacionada con valores íntimos, armonía y plenitud interior, conexión con el otro y estimulación del interés por los demás, en unidad con la vida, la naturaleza y el universo*(34)*. De este modo, los estudios muestran que una mayor participación en la religión/espiritualidad está asociada con indicadores psicológicos de bienestar y con menos depresión, ideación y conductas suicidas, y con menor consumo de drogas y alcohol*(25,34)*.

Entre las prácticas espirituales*(4)* se destaca el cuidado espiritual que se proporciona a los pacientes mientras se encuentran hospitalizados por el covid-19, y no solo los pacientes y sus familias son quienes lo requieren, sino que también los trabajadores de la salud, ya que necesitan alcanzar el bienestar a través de este tipo de prácticas.

En tal sentido, existen programas de cuidado espiritual para los profesionales de la salud, para quienes trabajan en primera línea, especialmente en hospitales y residencias sanitarias, en donde el rol de la fe y del cuidado espiritual es imperativo y debe ser ofrecido activamente por equipos especializados en este tipo de cuidados, definidos como multi religiosos/no religiosos, de capellanía/cuidado espiritual*(4)*. En dichos programas se describe la existencia de prácticas como la consejería espiritual, servicios de adoración, meditación, lectura de la biblia u otras actividades similares, las que pueden ser realizadas en modalidad presencial o mediante plataformas *online*.

El cuidado es una actividad inherente al plano espiritual, ya que los aspectos físicos de la enfermedad y el sufrimiento mental demandan una forma más compasiva de cuidados en salud*(9)*, en la que se debe caminar con las personas acompañándolos en su dolor*(23)*. En este sentido, el cuidado pastoral y otros servicios espirituales son una parte integral del cuidado en salud y de la vida diaria, teniendo las intervenciones religiosas y espirituales un rol crucial durante la pandemia, ya que proporcionan una guía a las personas*(23)*.

Sobre lo anterior, existen beneficios del apoyo espiritual y que, en el caso de pacientes con enfermedades avanzadas, y los que están al final de la vida, también pueden encontrar consuelo a través de la oración, o solo en la presencia de alguien que sostenga sus manos y que este con ellos cuando dan su último respiro*(40)*. Estas acciones fueron descritas por los participantes de este estudio como prácticas espirituales para acompañar a las personas que fallecían por el covid-19 y también para afrontar el dolor que significó la pérdida de tantas personas. Se reconoce que las creencias espirituales, como parte de la espiritualidad, son un poderoso mecanismo de afrontamiento cuando ocurren situaciones críticas o traumáticas, frente a la ansiedad y depresión, ya que ayuda con el optimismo, fe y esperanza*(37)*.

Desde la fragilidad experimentada con el covid-19 en las unidades de cuidado intensivo (UCI), el equipo de salud pudo descubrir o redescubrir la dimensión espiritual propia de toda persona que, por las medidas tomadas para enfrentar lo desconocido de la pandemia, fue dejado de lado, considerando que lo fundamental era sobrevivir.

Como conclusión es posible señalar que la espiritualidad en la asistencia sanitaria ha tomado mayor importancia luego de observar las consecuencias que ha dejado la pandemia por covid-19. El aislamiento y el desgaste físico y emocional del personal de salud derivó en transformaciones profundas en la perspectiva de ver a la persona. Esto ha propiciado la oportunidad de reflexionar sobre lo que implica la espiritualidad como dimensión integral de esa persona. Dicha dimensión debe ser pensada no solo desde el cuidado hacia el otro, sino que también, como cuidado de uno mismo, lo que se entiende como autocuidado. Sobre esto, el equipo de salud desplegó diversas estrategias o acciones vinculadas con la espiritualidad que les permitieron sobrellevar las dificultades propias de la pandemia. Se destaca que las creencias espirituales les permitieron tener consuelo frente a la muerte de sus pacientes y encontrar sentido a la vida. Asimismo, hicieron cambios en sus estilos de vida como parte del autocuidado, desarrollando la meditación, el contacto con la naturaleza, fortaleciendo relaciones significativas con sus seres queridos, relevando aspectos éticos y humanos en su trabajo, destinando momentos para dialogar y apoyarse en lo que estaban viviendo, potenciando así su compromiso con resto del equipo. De igual modo, quienes se declararon creyentes también desarrollaron la espiritualidad mediante la oración y la práctica de rituales religiosos con los pacientes moribundos y fallecidos, lo cual les generó paz y bienestar espiritual que contribuyó al autocuidado.

A pesar de todo lo que se sabe de la importancia del cuidado espiritual, los participantes de esta investigación experimentaron el sin sentido de la existencia humana, al ver morir en completa soledad a sus pacientes debido al miedo por el contagio y a las medidas institucionales que se tomaron para enfrentar lo desconocido de la pandemia. Sin embargo, ello también los llevó a reconocer que la dignidad del ser humano es más importante que cuidarse del temor al contagio y padecer las consecuencias de la enfermedad.

En consecuencia, los equipos de salud pudieron descubrir o redescubrir la importancia de la dimensión espiritual propia de toda persona, dimensión que reconocen vinculada a las relaciones que se establecen con los pacientes, las familias de éstos, las propias familias y el vínculo entre los colegas. Relaciones que se expresan habitualmente en prácticas cercanas, las que fueron consideradas por los entrevistados como fuentes de sentido y estímulo para dar continuidad a su dura tarea.

En esta investigación es posible reconocer que el espíritu del personal de salud se recompuso y fortaleció con mínimos gestos y actitudes que se creían imposibles de realizar. Y que la clave de este cambio estuvo en aceptar la propia debilidad ante el dolor y sufrimiento de los pacientes, cuestión que les posibilitó volver a sentir, actuar y ser conforme a lo que creían, esperaban y amaban de la vida.

Por lo tanto, frente a los desafíos actuales que presenta el sistema de salud, tales como lo vivido durante la pandemia, la espiritualidad debe ser considerada en la atención que se brinda al paciente y su familia, así como también al personal de salud que requiere de cuidados espirituales como parte de su autocuidado y bienestar, todo lo cual lleva al imperativo ético de humanizar las instituciones de salud.

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EXPLORING FACTORS INFLUENCING ETHICAL MARKETING OF BIOMEDICAL PRODUCTS: A CASE STUDY IN PAKISTAN

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Abstract: This study examines the impact of socio-cultural factors and informal business networks on ethical marketing practices in the biomedical industry of Gilgit-Baltistan, Pakistan. Using a qualitative research approach, data were collected through in-depth interviews with 36 respondents, including healthcare providers, biomedical product distributors, and local business stakeholders. Thematic analysis identified six major themes: (1) Trust-Based Marketing & Relationships, (2) Informal Business Networks & Influence, (3) Cultural & Community Influence, (4) Ethical Challenges & Trade-offs, (5) Traditional & Incentive-Driven Marketing, and (6) Regulatory Barriers & Compliance Issues. Findings indicate that trust-based relationships, word-of-mouth referrals, and informal agreements significantly shape marketing strategies, often at the cost of ethical transparency and regulatory compliance. Moreover, cultural expectations and social credibility outweigh formal ethical guidelines, leading to ethical trade-offs and weak policy enforcement. The study highlights the need for context-sensitive ethical marketing frameworks that balance local socio-cultural values with formal regulatory requirements. Strengthening policy interventions, regulatory oversight, and ethical awareness campaigns could help to mitigate the dominance of informal business networks and enhance compliance in biomedical marketing. The findings contribute to the broader discourse on business ethics, marketing regulations, and the role of socio-cultural norms in shaping commercial practices in developing regions.

Keywords: ethical marketing, informal business networks, socio-cultural influence, biomedical industry, Gilgit-Baltistan, trust-based marketing, regulatory compliance

Exploración de los factores que influyen en la comercialización ética de productos biomédicos: un estudio de caso en Pakistán

Resumen: Este estudio examina el impacto de los factores socioculturales y las redes empresariales informales en las prácticas de marketing ético en la industria biomédica de Gilgit-Baltistán, Pakistán. Mediante un enfoque de investigación cualitativo, se recopilaron datos mediante entrevistas exhaustivas con 36 encuestados, entre ellos profesionales sanitarios, distribuidores de productos biomédicos y actores empresariales locales. El análisis temático identificó seis temas principales: (1) Marketing y relaciones basadas en la confianza, (2) Redes empresariales informales e influencia, (3) Influencia cultural y comunitaria, (4) Desafíos éticos y compensaciones, (5) Marketing tradicional e impulsado por incentivos, y (6) Barreras regulatorias y problemas de cumplimiento. Los hallazgos indican que las relaciones basadas en la confianza, las recomendaciones boca a boca y los acuerdos informales configuran significativamente las estrategias de marketing, a menudo a expensas de la transparencia ética y el cumplimiento normativo. Además, las expectativas culturales y la credibilidad social prevalecen sobre las directrices éticas formales, lo que genera compensaciones éticas y una aplicación deficiente de las políticas. El estudio destaca la necesidad de marcos de marketing ético sensibles al contexto que equilibren los valores socioculturales locales con los requisitos regulatorios formales. El fortalecimiento de las intervenciones políticas, la supervisión regulatoria y las campañas de concienciación ética podrían ayudar a mitigar el predominio de las redes comerciales informales y a mejorar el cumplimiento normativo en el marketing biomédico. Los hallazgos contribuyen a un discurso más amplio sobre la ética empresarial, la normativa de marketing y el papel de las normas socioculturales en la configuración de las prácticas comerciales en las regiones en desarrollo.

Palabras clave: marketing ético, redes comerciales informales, influencia sociocultural, industria biomédica, Gilgit-Baltistán, marketing basado en la confianza, cumplimiento normativo

Explorando fatores que influenciam o marketing ético de produtos biomédicos: um estudo de caso no Paquistão

Resumo: Esse estudo examina o impacto de fatores sócio-culturais e de redes empresariais informais sobre práticas de marketing ético na industria biomédica de Gilgit-Baltistan, Paquistão. Usando uma abordagem de pesquisa qualitativa, foram coletados dados através de entrevistas em profundidade com 36 sujeitos, incluindo prestadores de cuidados à saúde, distribuiudores de produtos biomédicos e partes interessadas de negócios locais. Análise temática identificou seis temas principais: (1) Marketing e Relacionamentos Baseados em Confiança, (2) Redes de Negócios Informais e Influência, (3) Influência Cultural e Comu-

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nitária, (4) Desafios Éticos e Compensações, (5) Marketing Tradicional e Baseado em Incentivos, e (6) Barreiras Regulatórias e Questões de Conformidade. Os resultados indicam que relações baseadas na confiança, referências boca-a-boca e acordos informais moldam significativamente estratégias de marketing, frequentemente à custa da transparência ética e de conformidade regulatória. Além disso, expectativas culturais e credibilidade sócia superam diretrizes éticas, levando a compensações éticas e fraca aplicação de políticas.O estudo ressalta a necessidade de estruturas de marketing ético sensíveis ao contexto, que equilibrem valores sócio-culturais locais com requisitos regulatórios formais. Reforçar intervenções políticas, supervisão regulatória e campanhas de consciência ética pode ajudar a mitigar a dominância de redes empresariais informais e aumentar a conformidade no marketing biomédico.Os achados contribuem para ampliar o discurso sobre ética empresarial, regulações de marketing e o papel de normas sócio-culturais moldarem práticas comerciais em regiões em desenvolvimento.

Palavras-chave: marketing ético, redes empresariais informais, influência sócio-cultural, indústria biomédica, Gilgit-Baltistan, marketing baseado na confiança, conformidade regulatória

Introduction

The ethical promotion of biomedical products is crucial for maintaining transparency, customer confidence, and adherence to regulations in the healthcare industry. In areas with insufficient regulatory supervision, like Gilgit-Baltistan (GB), Pakistan, ethical dilemmas in biomedical marketing are significantly exacerbated. Marketing biomedical products in rural regions necessitates harmonizing of commercial goals and moral standards, guaranteeing that healthcare providers and consumers have precise, evidence-based information devoid of deceptive assertions or unethical advertising strategies*(1)*.

This study examines the principal elements affecting the ethical marketing of biomedical items in the rural healthcare markets of GB, Pakistan. The region encounters distinct obstacles, such as inadequate regulatory enforcement, insufficient understanding of ethical standards, and market pressures that could result in compromised marketing tactics. Ethical difficulties including disinformation, conflicts of interest, pricing transparency, and the influence of informal networks in product promotion are significant matters that require examination*(2)*.

Using a qualitative technique, this study collects data through in-depth interviews with 36 respondents working in biomedical product marketing, including sales representatives, distributors, and industry specialists. Their experiences and insights thoroughly comprehend the ethical dilemmas they face and the external influences shaping their marketing strategies. The study employs thematic analysis to identify the principal drivers and obstacles to ethical marketing practices in this rural healthcare context*(3)*.

The research elucidates these factors, thereby enhancing the broader discourse on ethical business practices within the healthcare sector. The findings will provide critical insights for policymakers, regulatory bodies, and industry stakeholders to formulate strategies that foster ethical compliance, bolster consumer protection, and enhance the overall integrity of biomedical product marketing in GB, Pakistan.

Research Questions

Regulatory Frameworks – How do existing regulations and enforcement mechanisms impact ethical marketing practices in the biomedical sector of rural Gilgit-Baltistan?

Market Competition – In what ways does market competition influence the ethical decision-making of biomedical product marketers in rural areas?

Consumer Awareness – How does the level of awareness among healthcare providers and consumers affect ethical compliance in biomedical product marketing?

Socio-Cultural Influences – How do local socio-cultural factors and informal business networks shape ethical marketing practices in the biomedical industry of Gilgit-Baltistan?

Literature review

Ethical Marketing in the Biomedical Industry

Ethical marketing in the biomedical sector is essential for maintaining transparency, trust, and integrity in the promotion and sale of medical products. Biomedical products, such as medical instruments, diagnostic tools, and pharmaceutical supplies, significantly influence human health, rendering ethical issues essential. Ethical marketing denotes the commitment to equitable, transparent, and accountable promotional practices that emphasise patient safety, the accurate transmission of information, and conformity to industry standards. The biomedical sector has distinct issues, such as deceptive advertising, inflated product assertions, and conflicts of interest between manufacturers and healthcare practitioners. Ethical difficulties frequently emerge when profit-oriented goals eclipse consumer welfare, resulting in apprehensions regarding misinformation, unethical marketing methods, and partial endorsements. Due to the sensitive nature of biomedical products, rigorous compliance with ethical requirements is necessary to uphold credibility and safeguard public health*(4)*.

The biomedical industry functions under a regulatory framework intended to guarantee that marketing efforts conform to ethical standards. The efficacy of these restrictions differs by area, especially in developing economies where oversight systems may be inadequate. In rural regions like Gilgit-Baltistan, Pakistan, ethical marketing issues are intensified by limited regulatory enforcement, insufficient understanding among healthcare professionals, and the impact of informal business networks. Research has indicated that in these environments, aggressive sales strategies, inappropriate incentives, and the absence of standardised marketing protocols frequently result in ethical violations. Confronting these difficulties necessitates a comprehensive strategy, encompassing more robust regulatory rules, improved consumer education, and collective industry initiatives to advocate ethical marketing practices. By comprehending the fundamental principles of ethical marketing within the biomedical sector, researchers and policymakers can strive for more sustainable and responsible marketing methods that advantage both enterprises and public health*(5)*.

Regulatory Frameworks and Ethical Compliance in Biomedical Marketing

Regulatory frameworks establish the basis for ethical compliance in biomedical marketing, offering norms that regulate promotional techniques, transparency, and consumer protection*(6)*. These policies aim to prohibit unethical marketing practices, including false advertising, deceptive claims, and improper cooperation between manufacturers and healthcare professionals. Internationally, entities like the U.S. Food and Drug Administration (FDA), the European Medicines Agency (EMA), and the World Health Organisation (WHO) establish rigorous marketing regulations to guarantee the responsible promotion of biomedical products. In underdeveloped nations, regulatory enforcement is frequently inadequate, resulting in vulnerabilities that permit unethical practices to thrive. The lack of stringent oversight procedures results in unregulated promotional methods, where profit-oriented incentives occasionally supersede ethical considerations. Consequently, customers, especially in rural regions, are susceptible to disinformation, resulting in impaired healthcare decisions*(7)*.

In Pakistan, regulatory entities like the Drug Regulatory Authority of Pakistan (DRAP) supervise the marketing of pharmaceutical and biomedical products. Nevertheless, enforcement in rural areas such as Gilgit-Baltistan is constrained by logistical difficulties, resource limitations, and insufficient monitoring infrastructure. Numerous biomedical marketers function within a milieu where informal networks, interpersonal interactions, and commercial motivations substantially influence marketing strategies. This generates a situation in which ethical adherence is not rigorously maintained, and regulatory frameworks are more theoretical than practical. Enhancing ethical compliance necessitates not only the existence of regulations but also their effective execution, consistent monitoring, and rigorous punishments for infractions. Furthermore, educating healthcare practitioners and biomedical marketers on ethical norms and regulatory mandates can enhance compliance and mitigate unethical marketing tactics. Confronting these regulatory issues is essential to guarantee that biomedical marketing fulfils its intended role of delivering accurate, transparent, and morally responsible product information to healthcare providers and consumers*(8)*.

Market Competition and Its Impact on Ethical Marketing Practices

Market competitiveness significantly influences ethical marketing strategies within the biomedical sector. In a very competitive industry, companies frequently endeavour to optimise sales and market share, which may occasionally result in ethical concessions. Fierce rivalry among biomedical product makers and distributors may compel marketers to adopt aggressive promotional tactics, such as overstated product claims, deceptive marketing, and financial inducements for healthcare practitioners. Such techniques might compromise medical decision-making, since healthcare practitioners may be swayed by marketing strategies instead of objective product effectiveness. Companies often prioritise immediate financial profits over long-term ethical considerations, thus jeopardising patient safety. Ethical marketing, however, demands that businesses combine competition with responsibility, ensuring that promotional efforts fit with regulatory standards and encourage openness*(8)*.

In remote areas such as Gilgit-Baltistan, Pakistan, the constraints of market competition are exacerbated by insufficient consumer awareness, inadequate regulatory enforcement, and the prevalence of informal business networks. Due to a scarcity of established healthcare facilities and the absence of standardised procurement procedures, biomedical marketers frequently depend on personal contacts and financial incentives to obtain contracts and enhance sales. This fosters an atmosphere in which unethical activities, such as underreporting product hazards or exaggerating advantages, proliferate*(9)*.

Moreover, smaller biomedical enterprises competing against larger global corporations may feel pressured to employ aggressive marketing strategies to establish a presence in the market. Resolving these difficulties necessitates enhanced monitoring, ethical training for sales personnel, and a transition to value-centric marketing strategies that prioritise product quality, safety, and enduring consumer trust over short-term competitive gains. By fostering equitable competition and adherence to ethical standards, the biomedical sector may guarantee that marketing strategies enhance healthcare results instead of solely advancing commercial interests*(10, 11)*.

Consumer Awareness and Ethical Decision-Making in Biomedical Product Marketing

Consumer awareness is crucial in influencing ethical decision-making in biomedical product marketing, as knowledgeable consumers and healthcare practitioners are less vulnerable to deceptive claims and unethical sales practices. Informed decision-making depends on precise product information, transparent pricing, and a comprehensive awareness of the risks and advantages related to biomedical products. In rural areas such as Gilgit-Baltistan, restricted access to healthcare education and insufficient awareness of industry norms can render customers susceptible to unethical marketing methods*(12)*. Numerous healthcare practitioners and purchasers depend on sales reps as their principal source of product information, potentially resulting in biased decision-making if the information presented is inaccurate or exaggerated. The lack of independent verification systems intensifies this problem, enabling unethical marketing practices to flourish. Enhancing consumer knowledge via educational initiatives, training programs for healthcare professionals, and transparent marketing strategies can enable consumers to make ethical and informed decisions. Furthermore, regulatory authorities must implement regulations mandating biomedical firms to furnish accurate, evidence-based information to ensure the maintenance of ethical marketing practices throughout the sector*(13)*.

Socio-Cultural Influences on Ethical Marketing in Rural Healthcare Markets

Socio-cultural aspects significantly influence ethical marketing practices in rural healthcare markets, affecting customer behavior and corporate strategy. In areas such as Gilgit-Baltistan, conventional business procedures, human ties, and communal trust significantly influence the marketing and sale of biomedical products. Numerous rural healthcare providers and consumers depend on informal recommendations and personal networks instead of official regulatory requirements when making purchasing selections. This dependence on informal trust-based systems can occasionally supersede ethical considerations, as marketing professionals may prioritize relationship cultivation over transparent product information. Cultural norms around authority and hierarchy may render consumers reluctant to confront healthcare providers or sales personnel, permitting biased or misleading marketing strategies to remain unquestioned*(14)*.

A significant socio-cultural factor is the inclination towards fast economic gains, which can affect marketing efforts in ways that contradict ethical standards. Incentives, including commissions, gifts, or cash prizes, may be provided to healthcare providers, in return for product endorsements, regardless of whether those items adhere to the highest ethical or medical standards. Additionally, local attitudes and views regarding healthcare items, particularly distrust towards novel technologies or foreign medical devices, might influence marketing narratives in ways that may not consistently adhere to ethical standards. Confronting these socio-cultural forces necessitates a customized strategy that honors local customs while advocating for ethical marketing practices. This can be accomplished by culturally attuned awareness initiatives, enhanced community involvement, and policies that bolster ethical decision-making in the marketing of biomedical products*(15)*.

Challenges in Implementing Ethical Marketing Strategies in Developing Regions

Executing ethical marketing tactics in underdeveloped nations is intricate due to inadequate regulatory enforcement, market-driven pressures, and socio-economic limitations. A primary difficulty is the absence of stringent regulatory oversight in the marketing of biomedical products. Numerous developing nations, such as Pakistan, possess ethical marketing norms; nevertheless, enforcement is hindered by resource constraints and ineffective monitoring systems. Consequently, unethical tactics including deceptive ads, inflated assertions, and inappropriate inducements to healthcare providers persist unabated. The lack of standardized standards across several locations exacerbates compliance challenges, allowing corporations to exploit regulatory loopholes to enhance sales*(16)*. A notable obstacle is the economic and competitive pressures, encountered by biomedical firms functioning in resource-limited settings. In fiercely competitive markets with constrained customer purchasing power, enterprises frequently emphasize immediate financial profits over ethical considerations. Sales-oriented marketing methods, such as assertive promotions and incentives for healthcare providers, may result in ethical compromises. Furthermore, insufficient consumer awareness and education in rural areas facilitate the proliferation of unethical marketing practices *(13)*. Numerous healthcare practitioners and consumers are deprived of dependable product information, heightening their reliance on sales personnel who may offer biased or inaccurate information. Addressing these difficulties necessitates a multifaceted strategy, encompassing enhanced regulatory frameworks, ethical training initiatives for marketers, and awareness campaigns to empower consumers. Enhancing ethical compliance in biomedical marketing can ultimately improve public health outcomes and bolster faith in the healthcare system *(17)*.

Gaps in Existing Literature and Future Research Directions

Notwithstanding the increasing focus on ethical marketing within the biomedical industry, notable deficiencies persist in the current literature, especially regarding its use in underdeveloped and rural areas. The majority of research on biomedical marketing ethics concentrates on industrialized nations, characterized by established regulatory frameworks and consumer awareness*(18)*. Nonetheless, there exists a paucity of studies about the impact of inadequate regulatory oversight, socio-cultural factors, and economic limitations on ethical marketing practices in emerging areas, like Gilgit-Baltistan, Pakistan. Moreover, although studies examine the impact of legislation on ethical compliance, there is a lack of studies regarding the efficacy of enforcement mechanisms, and the influence of informal business networks on marketing ethics in rural healthcare markets*(19)*.

Future research should investigate context-specific ethical marketing difficulties in impoverished nations, specifically focusing on the interplay of legislative frameworks, consumer behavior, and competitive forces. There is a necessity for empirical research that evaluates the actual effects of unethical marketing on patient outcomes and trust in healthcare providers. Furthermore, research may explore novel approaches to advancing ethical marketing, including the impact of digital technologies, public awareness initiatives, and corporate social responsibility efforts *(20)*. A comparative analysis of ethical marketing practices between developed and developing regions may provide insights into optimal practices and adaptive regulatory frameworks. Addressing these gaps will enhance the knowledge of ethical marketing difficulties and facilitate the development of sustainable solutions suited to various economic and cultural contexts*(21)*.

Methodology

To investigate the elements that have an impact on the ethical marketing of biomedical products in the rural areas of Gilgit-Baltistan, Pakistan, this study makes use of a qualitative research design. To acquire a comprehensive understanding of the experiences, viewpoints, and ethical problems that are encountered by professionals working in the biomedical marketing industry, a qualitative approach was selected as the method of investigation. A comprehensive understanding of the regulatory, socio-cultural, and market-driven elements that impact marketing practices can be achieved through the use of qualitative research methodologies. This is especially important when considering the complexity of ethical considerations in the marketing of biomedical products*(22)*.

Procedure for the Accumulation of Data

The information required for this study was gathered by conducting in-depth, semi-structured interviews with a total of twenty-six respondents who were currently employed in fields that were associated with biomedical items. Choosing this strategy was done to provide participants with the opportunity to freely express their opinions while also ensuring that important topics concerning ethical marketing practices were discussed. Regulatory compliance, competitive pressures, socio-cultural factors, and consumer awareness were some of the topics that were discussed throughout the interviews when it came to biomedical marketing. The duration of each interview ranged from forty-five to sixty minutes, and it was carried out either in person or through online communication platforms, depending on the availability of the individuals who attended the interviews.

Before completing the interviews, informed consent was sought from every participant to guarantee the study's authenticity and ensure that it adhered to ethical standards. The participants were given the assurance that their responses would be kept anonymous and would only be used for the study. In addition, ethical criteria were adhered to in a stringent manner, which ensured that no respondent was forced to take part in the study and that they were allowed to withdraw from the research at any point in time. To conduct research that involved human participants, the study was conducted by the ethical criteria that have been established by international research organizations such as the American Psychological Association (APA) and the Declaration of Helsinki of the World Medical Association.

The techniques of data analysis are as follows:

A thorough qualitative data analysis procedure was carried out on the gathered information, and thematic analysis methodologies were utilized throughout the process. An approach to qualitative research that is widely accepted is called thematic analysis*(23)*. This approach entails systematically detecting, analyzing, and reporting on patterns (themes) that are present within the data. The following procedures were carried out throughout the analysis:

1. Data Familiarization. Each and every interview transcript was reviewed and reread with great attention to detail in order to accumulate a comprehensive comprehension of the material. This stage was helpful in determining the initial patterns and areas of conversation that needed to be addressed.

2. Coding. The transcripts were coded in a methodical manner, with significant terms and concepts that were repeated being tagged with brief descriptive phrases. The use of open coding made it possible for themes to emerge from the data in a manner that was entirely objective*(24)*.

3. Sorting and Sifting. After that, the codes were arranged into more general categories by categorizing them according to the similarities and connections that existed between the various codes. While going through this procedure, it was necessary to combine categories that overlapped and make sure that distinct themes were preserved*(25)*.

4. Tabulation and Data Organization. The themes were arranged into structured categories, which made it simpler to examine patterns and arrive at findings that have significance*(25)*.

5. Thematic Code Development. Following the classification process, the thematic codes were established that were based on the themes that occurred the most frequently and were the most significant from an analytical standpoint*(26)*.

Following the identification of the themes, the findings were organized in such a way as to emphasize the important elements that influence ethical marketing in the distribution and promotion of biomedical products by means of the result formulation process.

Validity and reliability of data

A number of different qualitative validation methods were utilized in order to improve the reliability of the study, including the following:

The findings were cross-verified and consistency was ensured through the use of triangulation, which involves using multiple sources of data (different respondents from different biomedical marketing jobs).

Following the completion of the theme analysis, the most important findings were discussed with a few of the participants for the purpose of validation. This was done to guarantee that their perspectives were appropriately portrayed*(27).*

- Inter-Coder Reliability. In order to reduce the possibility of bias, the coding was checked independently by a number of researchers in order to guarantee that the identification of themes was consistent.

- Audit Trail. In order to guarantee both repeatability and transparency, comprehensive records of the data collection, coding process, and analytic processes were kept.

In order to ensure that the findings of the study adequately portrayed the lived experiences and ethical problems that are encountered by biomedical product marketers, the use of thematic analysis provided a systematic yet flexible method to the interpretation of qualitative data. The findings that were generated from this analysis add to a deeper knowledge of how ethical considerations are managed in the process of marketing biomedical products in developing countries, particularly in rural settings that are resource-constrained, such as Gilgit-Baltistan.

Data Analysis

The data analysis section provides insights obtained from comprehensive interviews with 36 participants employed in biomedical product marketing in rural Gilgit-Baltistan. A theme analysis was performed to discern principal trends, classify responses, and establish sub-thematic codes that represent the determinants affecting ethical marketing practices. The data was methodically coded, categorized, and examined using qualitative methods, assuring both validity and reliability. The results are organized according to four principal research questions, with each part emphasizing the predominant themes and sub-themes that arose from the respondents' viewpoints.

Analysis for- *Regulatory Frameworks*

Tables 1 to 8 are published at the end of the article.

Regarding the influence that pre-existing legislation and enforcement procedures have on ethical marketing practices in the biomedical sector in rural Gilgit-Baltistan, the responses of 36 participants are presented in Table 1. Several important concerns, including inadequate regulatory enforcement, a lack of oversight, unfair competition, and inadequate consumer protection, are brought to light by the solutions offered. Several of the respondents underlined that although there are restrictions in place, they are frequently not implemented properly, which allows unethical marketing techniques to continue with impunity. In addition, the task of sustaining ethical marketing standards is compounded by a number of factors, including policies that have become obsolete, the absence of consequences, and regulatory inefficiencies. The thematic codes that were developed from these comments offer insights into the major aspects that influence ethical compliance, as well as the necessity of more stringent enforcement, improved training, and independent regulatory monitoring.

In Table 2, the distribution of sub-thematic codes is presented under important representative words. This table also highlights the elements that influence ethical marketing in the biomedical sector of rural Gilgit-Baltistan. In the table, comments from thirty-six participants are organized into seven primary themes, each of which is accompanied by a sub-theme that reflects the regulatory, consumer, business, and competitive difficulties that are present in the sector or industry.

The most prominent concerns are regulatory weakness and a lack of control, with each item accounting for 19.44% of the replies. Among these are problems such as insufficient enforcement, limited resources, an absence of audits, the presence of confusing legislation, and unscrupulous practices. The fact that consumer protection issues, such as a lack of information, the prevalence of counterfeit items, and unclear legal implications, make up 16.67 percent of replies exemplifies the dangers that end-users confront in a market that is inadequately regulated.

Concerns regarding misleading marketing techniques, a lack of ethical incentives, and the requirement for tougher legislation and independent scrutiny are reflected in the fact that both ethical business difficulties and the need for legislative reforms account for 13.89% of the total. The impact of unfair competition and legal loopholes on ethical marketing practices is highlighted by the competitive pressure phenomenon, which accounts for 11.11 percent of the total. Finally, although training and awareness gaps are the least represented component, they show a significant need for capacity-building activities to increase ethical marketing standards. This is despite the fact that they are the least represented aspect.

Analysis for- Market Competition

Table 3 provides insights into how market competition influences the ethical decision-making of biomedical product marketers in rural areas. The responses highlight various challenges, such as price pressure, misleading marketing tactics, and unfair competition, which force marketers to navigate ethical dilemmas. Many respondents expressed concerns over regulatory weaknesses and the lack of enforcement, allowing unethical practices to thrive. Additionally, economic constraints and consumer awareness gaps further complicate ethical marketing efforts. This table categorizes these responses under distinct thematic codes, reflecting the diverse factors shaping ethical decision-making in a competitive market.

Table 4 presents a statistical analysis of the principal elements affecting ethical decision-making in the marketing of biomedical products in rural markets. The primary issue, competitive pressure, constitutes 16.67% of respondents, signifying that market rivalry compels enterprises to implement aggressive techniques, compromise ethical standards, and perpetually modify their marketing plans. Likewise, deceptive marketing techniques account for 16.67%, underscoring prevalent issues such as misleading promotions, inaccurate product assertions, and unethical manipulation of stakeholders. Regulatory deficiencies, accounting for 13.89% of replies, highlight the prevalence of illicit market rivalry, inadequate enforcement, and corruption, enabling unscrupulous rivals to prevail.

Economic restraints, such as market domination and financial limitations, account for 8.33%, indicating that smaller enterprises have challenges in competing with larger corporations with superior resources. Consumer awareness and educational deficiencies constitute 11.11%, highlighting the issue of disinformation and the necessity for ethical training programs to assist customers in making informed choices. Bribery and unethical influence, at 8.33%, underscore improper financial inducements provided to healthcare personnel and regulatory entities. Ethical business issues, at 8.33%, suggest that companies emphasizing ethical procedures frequently lose clientele to competitors who partake in unethical behavior.

Market rivalry and pricing pressures account for 11.11% of respondents, highlighting challenges such as price wars, unsustainable pricing, and the absence of price control policies that compel enterprises to make immoral compromises. Finally, the necessity for policy reforms, however the least prevalent at 5.56%, indicates a significant requirement for ethical standards and governmental assistance to foster equitable market competitiveness.

Statistical findings indicate that market rivalry, coupled with regulatory loopholes and consumer deception, profoundly influences ethical decision-making in biomedical marketing. The elevated percentages linked to competitive pressure and misleading marketing indicate systemic issues necessitating regulatory action and consumer awareness programs. Implementing tougher policies, ethical training, and market laws could alleviate unethical marketing techniques and foster equitable commercial rivalry.

Q No. 3- Consumer Awareness

Table 5 displays the responses of 36 participants about the impact of knowledge levels among healthcare providers and customers on ethical compliance in biomedical product marketing. The comments illustrate varied viewpoints regarding the influence of knowledge, regulatory awareness, and customer comprehension on the formulation of ethical marketing strategies. Each response is categorized under a thematic key word to highlight recurring patterns in the data. This table offers significant insights on the relationship between awareness levels and compliance with ethical norms in the biomedical sector.

The replies in Table 6 from 36 participants have been classified into six sub-thematic key codes, each denoting a significant element affecting ethical compliance in biomedical product marketing. The frequency and percentage distribution of replies reveal critical areas where awareness influences compliance.

The predominant category, "Consumer Knowledge and Understanding" (7 replies, 19.44%), underscores the critical importance of customer awareness in upholding ethical marketing practices. Respondents identified issues including product difference, counterfeit danger, consumer irresponsibility, and ignorance of certification, indicating that disinformation and a lack of consumer understanding render them more susceptible to unethical marketing activities. The elevated response rate in this category highlights the necessity for enhanced consumer education programs.

The "Healthcare Provider Awareness" category (6 responses, 16.67%) highlights deficiencies in knowledge among medical practitioners. Primary concerns encompass physician knowledge, verification challenges, and peer influence, illustrating how healthcare personnel may inadvertently facilitate unethical marketing due to insufficient understanding or failure to authenticate product legitimacy. The understanding of ethical standards*(6 responses)* and the absence of interest*(19 responses)* suggest that not all healthcare providers are inclined to adhere to compliance rules.

Likewise, "Ethical Compliance Challenges" (6 replies, 16.67%) recognizes external influences and deceptive marketing tactics as significant impediments to ethical compliance. Themes include unethical influence*(8 responses)*, inaccurate information*(18 responses)*, and disinformation*(23 responses)* illustrate how unscrupulous marketers exploit awareness deficiencies. Furthermore, unintended promotion*(24 responses)* indicates that certain healthcare personnel may inadvertently advocate for non-compliant biomedical items.

The "Regulatory and Institutional Role" category (6 replies, 16.67%) emphasizes the function of public policies and institutions in fostering ethical compliance. Participants emphasized the significance of regulatory initiatives*(22 responses),* uniform awareness*(31 responses)*, and cooperative endeavors*(36 responses)* to close knowledge gaps and guarantee compliance at the institutional level. The replies suggest that government-supported awareness initiatives and training programs may significantly enhance ethical marketing practices.

The "Educational and Awareness Efforts" category (6 replies, 16.67%) highlights the influence of awareness initiatives on ethical decision-making. Participants emphasized the necessity for hospital training*(12 responses)*, media awareness*(28 responses)*, and ethical training*(35 responses)* to improve compliance. The findings indicate that organized education and ongoing awareness initiatives can markedly enhance ethical marketing standards.

Finally, "Impact of Awareness on Ethical Decision-Making" (5 replies, 13.89%) underscores the direct influence of awareness on ethical conduct. Themes include educated decision-making*(10 responses)*, prioritization of price over quality*(14 responses)*, and ethical scrutiny*(30 responses)* suggest that knowledgeable healthcare practitioners and customers are more inclined to make ethical decisions, hence diminishing the likelihood of unethical actions in biomedical marketing.

The findings indicate that awareness is essential for ethical compliance, with consumer information, healthcare practitioner education, regulatory enforcement, and organized awareness initiatives identified as primary factors. The relatively uniform distribution across most categories (16.67% for four groups) indicates that various factors affect compliance, necessitating a holistic strategy that includes consumers, providers, regulators, and institutions.

Q No. 4: Socio-Cultural Influences

This Table 7 categorizes responses into key themes that explain how local socio-cultural factors and informal business networks shape ethical marketing practices in the biomedical industry of Gilgit-Baltistan.

The table 8 classifies responses into six sub-thematic key codes, each reflecting a distinct facet of socio-cultural impacts on ethical marketing practices within the biomedical sector of Gilgit-Baltistan.

The predominant category, Cultural & Community Influence (25%), underscores the significant impact of local customs, word-of-mouth persuasion, and cultural norms on the formulation of marketing tactics. This indicates that ethical marketing approaches are frequently supplanted by community-driven decision-making, wherein social credibility is prioritized over regulatory compliance.

Trust-Based Marketing and Relationships (19.44%) and Ethical Challenges and Trade-offs (19.44%) hold equal importance. The former highlights the influence of personal relationships and supplier allegiance on marketing choices, frequently resulting in partial product endorsements. The latter elucidates ethical problems, when informal corporate relationships affect decision-making to the detriment of ethical openness.

Informal Business Networks & Influence (16.67%) elucidates how clandestine agreements and informal control mechanisms govern the promotion of biological products, frequently circumventing ethical requirements. This substantiates the idea that local marketing predominantly depends on informal talks instead of explicit policies.

Traditional and Incentive-Driven Marketing (13.89%) illustrates how enterprises utilize incentives and conventional networking tactics to achieve market supremacy, occasionally resulting in ethical ambiguities. Ultimately, Regulatory

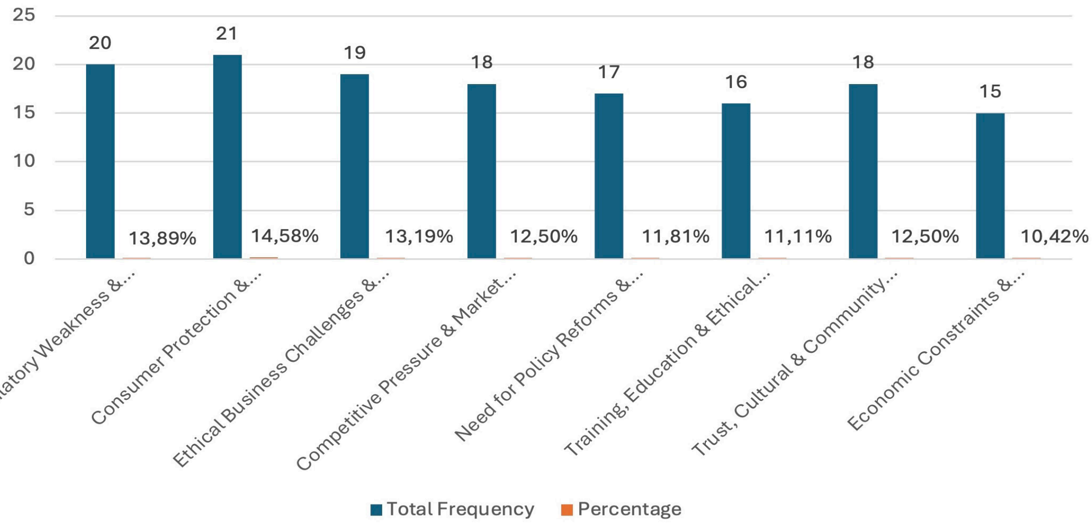

Figure 1 Factors Influencing Ethical Marketing of Biomedical Products

Barriers and Compliance Issues (5.56%) is the least reported category, suggesting that although regulatory challenges are present, they are eclipsed by robust cultural and informal business effects.

The findings indicate that socio-cultural elements and informal networks significantly influence biomedical marketing practices in Gilgit-Baltistan. Compliance with ethical marketing is frequently undermined by personal ties, cultural norms, and informal agreements, complicating the enforcement of conventional marketing ethics in the region.

Over all factors influencing ethical marketing of biomedical products.

Figure 1 shows over all comprehensive analysis of research. The ethical promotion of biomedical products is shaped by a confluence of regulatory, economic, competitive, and socio-cultural variables. A statistical examination of the principal themes extracted from qualitative research underscores the predominant issues influencing ethical standards in the marketing of these products.

Regulatory deficiencies and compliance challenges constitute a substantial obstacle to ethical marketing methods. The absence of stringent enforcement mechanisms and regulatory control results in inconsistent compliance with ethical standards, permitting unethical marketing practices to thrive. This problem is intensified by deficiencies in compliance monitoring, allowing enterprises to exploit regulatory gaps for competitive gain.

Concerns around consumer protection and awareness deficiencies are the most commonly reported issue, representing 14.58% of total replies. A significant number of consumers lack the requisite information to distinguish between ethically sold biomedical items and those advertised through deceptive claims. This underscores the pressing necessity for enhanced consumer education activities to improve informed decision-making and protect public health.

Ethical difficulties in business operations and the prevalence of misleading marketing methods constitute 13.19% of the complaints. Organizations frequently encounter tensions between ethical integrity and profit-oriented objectives, resulting in misinformation, inflated product claims, and opaque commercial practices. These problems underscore the imperative for more stringent ethical standards and accountability in biomedical marketing.

The fierce rivalry in the biomedical sector imposes considerable pressure on companies, necessitating the implementation of assertive marketing strategies. Market limitations, such as restricted resources and pricing difficulties, compel corporations to resort to potentially immoral actions to sustain their competitive advantage. The 12.50% prevalence of this issue highlights the necessity for regulatory authorities to implement equitable competition frameworks that foster ethical business practices.

A significant percentage (11.81%) of the data indicates the need for regulatory reforms and an enhanced institutional role in regulating ethical marketing. Numerous parties promote revised policies that tackle new difficulties in biomedical product marketing. Augmenting institutional participation in policy enforcement can improve ethical adherence throughout the sector.

Inadequate training and insufficient ethical awareness among healthcare providers and marketers lead to unethical marketing practices. This subject underscores the necessity for organized training programs to embed ethical concepts in professionals engaged in biomedical product marketing, with a prevalence of 11.11%. Improved education can reduce unethical decision-making and promote a culture of accountability.

The significance of trust, cultural dynamics, and community influence in biomedical marketing is apparent, comprising 12.50% of the responses. Informal networks and conventional belief systems frequently influence consumer views, impacting their purchase choices. Organizations must reconcile ethical marketing with culturally attuned communication techniques to uphold credibility and consumer trust.

Economic limitations, such as elevated marketing expenses and financial demands, frequently compel organizations to implement incentive-driven promotional techniques. This component, at 10.42%, underscores the ethical dilemmas linked to financial incentives in marketing. Although incentives can serve as an efficient mechanism, they must be regulated to avert unethical persuasive strategies that could deceive consumers.

Findings and Discussions

This study explores how socio-cultural factors and informal business networks shape ethical marketing practices in the biomedical industry of Gilgit-Baltistan, Pakistan. Given the region's strong reliance on trust-based relationships, community influence, and informal business dealings, ethical compliance in biomedical marketing often faces significant challenges. Through qualitative interviews with 36 respondents, the study identifies key themes that explain the complex interplay between local traditions, business ethics, and regulatory frameworks. The findings reveal that personal connections, informal networks, and socio-cultural norms significantly impact how biomedical products are marketed, often at the cost of ethical transparency and compliance.

Trust-Based Marketing & Personal Relationships

One of the most influential factors shaping marketing practices in Gilgit-Baltistan is trust-based marketing and relationship-driven transactions. The study finds that 19.44% of respondents highlighted the dominance of long-standing personal relationships in business decisions, particularly in the biomedical sector. Healthcare providers often prefer suppliers with whom they have personal or professional trust, sometimes at the expense of ethical standards. This aligns with existing research on relational contracting, where business ties take precedence over formal regulations.

Informal Business Networks & Ethical Trade-offs

A significant proportion (16.67%) of respondents pointed to the prevalence of informal business networks in marketing biomedical products. In such an environment, business deals are often finalized through informal agreements rather than structured regulatory frameworks. This raises ethical concerns, as these networks tend to bypass formal compliance mechanisms. Additionally, 19.44% of respondents indicated that ethical trade-offs occur frequently, where economic or business interests outweigh formal ethical considerations. This reflects a broader challenge where market dynamics are shaped more by social structures than by institutional policies.

Cultural and Community Influence

The most dominant factor identified in the study is the cultural and community influence on ethical marketing. 25% of respondents emphasized that word-of-mouth recommendations, cultural expectations, and local traditions play a decisive role in marketing practices. In rural regions, marketing success is less about regulatory compliance and more about social credibility. Businesses that integrate well into local cultural values are more likely to gain consumer trust, even if they do not adhere strictly to ethical standards. This insight underscores the importance of cultural adaptation strategies in business ethics discussions.

Traditional Marketing Strategies & Incentive-Driven Deals

Approximately 13.89% of respondents highlighted the role of traditional and incentive-driven marketing in shaping biomedical product promotion. Many businesses prefer to use long-established networking channels rather than standard ethical advertising techniques. In some cases, extra incentives or unofficial agreements between suppliers and healthcare providers influence product selection, raising concerns about fair competition and transparency. This finding suggests that monetary and social incentives often override ethical marketing regulations, making enforcement difficult.

Regulatory Barriers and Compliance Issues

Although regulatory compliance is an essential component of ethical marketing, only 5.56% of respondents explicitly mentioned regulatory barriers as a significant challenge. This suggests that formal ethical guidelines are not deeply embedded in the local business ecosystem. Businesses in Gilgit-Baltistan often operate outside strict regulatory frameworks, making it challenging for authorities to implement ethical marketing policies effectively. This aligns with broader concerns about the weak institutional oversight in rural economies, where formal regulations exist but are not strictly enforced.

Overall Discussion

The findings of this study highlight a fundamental disconnect between formal ethical marketing practices and socio-cultural realities in Gilgit-Baltistan. The biomedical sector, like many other industries in the region, relies heavily on informal relationships, community influence, and trust-based networks. These factors significantly shape consumer behavior and business decisions, often superseding ethical guidelines.

A major implication of this study is that ethical marketing frameworks in rural and culturally embedded economies must be tailored to local realities. Simply enforcing universal ethical standards may not be effective unless they integrate socio-cultural values. Policymakers and business leaders need to balance cultural norms with ethical best practices, ensuring that marketing strategies are both ethical and socially acceptable. Additionally, strengthening regulatory oversight and promoting awareness of ethical marketing principles among business stakeholders could help reduce reliance on informal networks. However, this requires collaborative efforts between policymakers, businesses, and community leaders to create a more transparent and ethically sustainable marketing environment.

Conclusion

This research provides valuable insights into the socio-cultural influences on ethical marketing in the biomedical industry of Gilgit-Baltistan. The dominance of trust-based relationships, informal business networks, and cultural influence suggests that ethical compliance is often compromised in favor of social and economic relationships. Addressing these challenges requires a contextualized approach to ethical marketing—one that respects local business practices while promoting transparency and accountability. Future research could further explore policy interventions and practical frameworks to bridge the gap between cultural business norms and ethical marketing compliance in rural economies.

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Table 1 Response for Q 1-Regulatory Frameworks

Respondent No.	Response	Thematic Code
1	I believe regulations exist, but enforcement is weak, leading to frequent ethical violations.	Weak Regulatory Enforcement
2	We follow the basic guidelines, but there is no strict monitoring, so some companies exploit loopholes.	Lack of Oversight
3	Our business tries to comply, but competitors use unethical marketing because authorities rarely intervene.	Unfair Competition
4	I see that local authorities are not well-trained to monitor ethical marketing practices.	Regulatory Inefficiency
5	We have no proper awareness of marketing ethics because regulatory guidelines are unclear.	Lack of Awareness
6	I think regulations exist only on paper, but in practice, there is no serious enforcement.	Paper-Only Regulations
7	We are forced to use aggressive marketing since there are no penalties for misleading claims.	Lack of Penalties
8	Our sales team struggles because unregulated competitors use false promises to attract customers.	Misleading Marketing
9	I feel there is a need for stricter rules to prevent unethical product promotion.	Need for Stricter Laws
10	We sometimes face ethical dilemmas because the rules are vague and open to interpretation.	Ambiguous Regulations
11	I rarely see regulators checking whether companies follow ethical marketing rules.	Minimal Inspections
12	Our region lacks proper consumer protection laws, so misleading marketing continues.	Weak Consumer Protection
13	I think authorities should impose strict fines on those who violate ethical marketing guidelines.	Need for Penalties
14	We try to be ethical, but without strict enforcement, many companies prioritize profit over ethics.	Profit Over Ethics
15	I believe regulators need more resources to monitor biomedical marketing effectively.	Resource Constraints
16	We have faced no audits in years, which makes unethical practices easy to continue.	Lack of Audits
17	I have seen fake or substandard biomedical products marketed due to poor regulations.	Presence of Fake Products
18	We often see companies bribing officials to bypass ethical marketing rules.	Corruption in Regulation
19	I feel that ethical marketing is difficult in a system where rules are not enforced fairly.	Unequal Enforcement
20	We struggle to maintain ethical marketing because competitors use unethical methods freely.	Competitive Pressure
21	I think rural markets are ignored when it comes to enforcing ethical regulations.	Regulatory Neglect
22	We need regulatory bodies to conduct regular awareness sessions about ethical marketing.	Need for Training
23	I notice that companies using unethical tactics are rarely held accountable.	Lack of Accountability
24	Our marketing team lacks proper ethical marketing training due to no formal industry guidelines.	Need for Ethical Training
25	I think implementing digital tracking systems can help regulate marketing ethics better.	Need for Digital Monitoring
26	We are unaware of any existing penalties for violating marketing ethics.	Unclear Legal Consequences
27	I feel that many regulations are outdated and do not reflect current market practices.	Outdated Policies
28	We try to follow ethical marketing, but loopholes in policies allow others to bypass rules.	Policy Loopholes
29	I have never been approached by a regulatory officer regarding our marketing practices.	No Active Monitoring
30	We sometimes lose customers because others use unethical tactics without consequences.	Ethical Business Disadvantage
31	I see foreign biomedical companies exploiting weak regulations to market products without oversight.	Exploitation by Foreign Firms
32	Our company has ethical marketing policies, but there is no incentive to follow them.	Lack of Ethical Incentives
33	I think an independent body should oversee ethical marketing instead of government agencies alone.	Need for Independent Oversight
34	We need stricter import regulations to prevent substandard biomedical products from entering the market.	Need for Import Control
35	I feel rural consumers are the most affected by unethical marketing due to lack of awareness.	Consumer Vulnerability
36	We must promote self-regulation in the industry if external enforcement remains weak.	Self-Regulation Need

Table 2 Distribution of Sub-Thematic Codes Under Key Representative Words and Percentage

Sub-Thematic Main Key Codes	Respondent Numbers	Freq.	Total	Percentage
Regulatory Weakness	1, 6, 11, 15, 16, 21, 29	7	7	19.44%
Weak Regulatory Enforcement	1	1		
Paper-Only Regulations	6	1		
Minimal Inspections	11	1		
Resource Constraints	15	1		
Lack of Audits	16	1		
Regulatory Neglect	21	1		

No Active Monitoring	29	1		
Lack of Oversight	2, 4, 7, 10, 18, 19, 23	7	7	19.44%
Lack of Oversight	2	1		
Regulatory Inefficiency	4	1		
Lack of Penalties	7	1		
Ambiguous Regulations	10	1		
Corruption in Regulation	18	1		
Unequal Enforcement	19	1		
Lack of Accountability	23	1		
Consumer Protection Issues	5, 12, 17, 26, 27, 35	6	6	16.67%
Lack of Awareness	5	1		
Weak Consumer Protection	12	1		
Presence of Fake Products	17	1		
Unclear Legal Consequences	26	1		
Outdated Policies	27	1		
Consumer Vulnerability	35	1		
Ethical Business Challenges	8, 14, 30, 32, 36	5	5	13.89%
Misleading Marketing	8	1		
Profit Over Ethics	14	1		
Ethical Business Disadvantage	30	1		
Lack of Ethical Incentives	32	1		
Self-Regulation Need	36	1		
Competitive Pressure	3, 9, 20, 28	4	4	11.11%
Unfair Competition	3	1		
Need for Stricter Laws	9	1		
Competitive Pressure	20	1		
Policy Loopholes	28	1		
Need for Policy Reforms	13, 25, 31, 33, 34	5	5	13.89%
Need for Penalties	13	1		
Need for Digital Monitoring	25	1		
Exploitation by Foreign Firms	31	1		
Need for Independent Oversight	33	1		
Need for Import Control	34	1		
Training and Awareness Gaps	22, 24	2	2	5.56%
Need for Training	22	1		
Need for Ethical Training	24	1		

Table 3 Responses on market competition and ethical decision making

Respondent Number	Response	Thematic Code
1	I sometimes feel pressured to lower prices, even if it affects product quality.	Price Pressure
2	We have to exaggerate product benefits to compete with others in the market.	Misleading Marketing
3	Our competitors use aggressive sales tactics, forcing us to do the same.	Competitive Pressure
4	I find it difficult to maintain ethical standards when others cut corners.	Ethical Dilemma
5	We struggle because unethical competitors offer cheaper, substandard products.	Unfair Competition
6	I have seen misleading advertising used just to attract more buyers.	Deceptive Advertising
7	We sometimes have to give financial incentives to doctors to promote our products.	Bribery in Marketing
8	I feel that ethical marketing is a disadvantage when competitors do not follow rules.	Ethical Disadvantage
9	Our company faces challenges because fake products are easily available in the market.	Market Fraud
10	I try to stay ethical, but the pressure to match competitors' prices is intense.	Competitive Ethics Struggle
11	We have to offer discounts beyond our profit margin to retain customers.	Unsustainable Pricing
12	I have seen unethical competitors influencing healthcare professionals unfairly.	Unethical Influence
13	We struggle to maintain trust when competitors use deceptive marketing.	Trust Issues
14	I sometimes worry that ethical practices slow down our sales growth.	Ethical vs. Profitability
15	We need stricter regulations to stop unethical competitive practices.	Need for Regulation
16	I have observed competitors making false claims about product effectiveness.	False Product Claims
17	Our company finds it hard to survive when illegal imports flood the market.	Illegal Market Competition
18	I feel that price wars affect product quality and ethical decision-making.	Price Wars
19	We are forced to compromise on marketing ethics to keep up with competition.	Ethics Compromise
20	I believe that strong branding helps in ethical marketing despite competition.	Ethical Branding
21	Our firm follows ethical guidelines, but we lose customers to cheaper alternatives.	Ethical Business Challenge
22	I think the lack of enforcement allows unethical marketers to dominate the industry.	Regulatory Weakness
23	We face difficulty in promoting ethical products when misinformation spreads easily.	Misinformation
24	I notice that companies without proper licenses are selling biomedical products.	Unlicensed Market Players

25	We often have to adjust our strategies to compete with unethical marketing tactics.	Strategic Adjustments
26	I think ethical decision-making in marketing needs more awareness and training.	Need for Ethical Training
27	I have seen competitors using fake certifications to gain customer trust.	Fake Certifications
28	We face difficulty when customers are unaware of the ethical standards of products.	Consumer Awareness Gaps
29	The lack of price control policies affects fair competition and ethical sales.	Price Control Issues
30	I feel that large firms dominate the market, leaving no space for ethical businesses.	Market Dominance
31	We need industry-wide ethical guidelines to ensure fair competition.	Need for Ethical Guidelines
32	I have seen unethical competitors bribing regulatory authorities.	Corruption in Regulation
33	Customers often choose cheaper, low-quality products due to financial constraints.	Economic Constraints
34	We need consumer education programs to encourage ethical purchasing choices.	Consumer Education
35	I believe that government subsidies for ethical companies could promote fairness.	Need for Government Support
36	Our marketing strategies must adapt continuously due to unethical competitive moves.	Marketing Adaptation

Table 4 Distribution of Sub-Thematic Codes Under Key Representative Words- Market Competition

Sub-Thematic Main Key Codes	Respondent Numbers	Freq.	
Competitive Pressure	3, 5, 10,19, 25, 36	6	16.67%
Competitive Pressure	3	1	
Unfair Competition	5	1	
Competitive Ethics Struggle	10	1	
Ethics Compromise	19	1	
Strategic Adjustments	25	1	
Marketing Adaptation	36	1	
Deceptive Marketing Practices	2, 6, 12, 13, 16, 27	6	16.67 %
Misleading Marketing	2	1	
Deceptive Advertising	6	1	
Unethical Influence	12	1	
Trust Issues	13	1	
False Product Claims	16	1	
Fake Certifications	27	1	
Regulatory Weakness	15, 17, 22, 24, 32	5	13.89 %
Need for Regulation	15	1	
Illegal Market Competition	17	1	
Regulatory Weakness	22	1	
Unlicensed Market Players	24	1	
Corruption in Regulation	32	1	
Economic Constraints	20, 30, 33	3	8.33 %
Ethical Branding	20	1	
Market Dominance	30	1	
Economic Constraints	33	1	
Consumer Awareness & Education	23, 26, 28, 34	4	11.11 %
Misinformation	23	1	
Need for Ethical Training	26	1	
Consumer Awareness Gaps	28	1	
Consumer Education	34	1	
Bribery & Unethical Influence	7, 9, 14	3	8.33 %
Bribery in Marketing	7	1	
Market Fraud	9	1	
Ethical vs. Profitability	14	1	
Ethical Business Challenges	4, 8, 21	3	8.33 %
Ethical Dilemma	4	1	
Ethical Disadvantage	8	1	
Ethical Business Challenge	21	1	
Market Competition & Pricing	1, 11, 18, 29	4	11.11 %
Price Pressure	1	1	
Unsustainable Pricing	11	1	
Price Wars	18	1	
Price Control Issues	29	1	
Need for Policy Reforms	31, 35	2	5.56%
Need for Ethical Guidelines	31	1	
Need for Government Support	35	1	

Table 5 Consumer Awareness

Respondent Number	Response	Thematic Key Word
1	I have noticed that many healthcare providers lack proper knowledge about biomedical product regulations.	Knowledge Gap
2	We struggle to market ethical products because consumers do not understand the importance of quality and safety.	Consumer Understanding
3	I feel that low awareness among doctors leads to them recommending substandard products.	Physician Awareness
4	We face challenges because healthcare providers often do not verify product authenticity before prescribing.	Verification Issues
5	Our company has difficulty promoting ethical marketing when consumers do not differentiate between genuine and fake products.	Product Differentiation
6	I have observed that many healthcare providers are unaware of the latest biomedical marketing ethical standards.	Ethical Standards Awareness
7	We sometimes have to spend extra resources on educating both doctors and consumers about ethical product use.	Educational Efforts
8	I think the lack of awareness allows unethical marketers to manipulate healthcare providers.	Unethical Influence
9	Our marketing strategies need to include awareness campaigns to ensure compliance with ethical guidelines.	Awareness Campaigns
10	I feel that informed healthcare providers are more likely to comply with ethical marketing regulations.	Informed Decision-Making
11	We often struggle to convince consumers about the risks of counterfeit biomedical products.	Counterfeit Risk
12	I believe that ethical compliance improves when awareness programs are implemented in hospitals and clinics.	Hospital Training
13	Consumers rarely ask about the certifications or approval status of biomedical products.	Consumer Negligence
14	Our ethical marketing efforts are not effective because most customers prioritize price over quality.	Price Over Quality
15	I have seen unethical marketers take advantage of the lack of awareness to sell unapproved products.	Exploitation of Ignorance
16	We need government-backed awareness initiatives to educate consumers and healthcare providers.	Need for Public Awareness
17	I feel that many patients blindly trust doctors without questioning the quality of prescribed biomedical products.	Patient Trust Issues
18	Our competitors often mislead customers who are unaware of the importance of ethical compliance.	Misleading Information
19	We conduct workshops for doctors, but many still lack interest in ethical compliance.	Lack of Interest
20	I have noticed that ethical compliance improves when hospitals enforce strict guidelines on product selection.	Institutional Enforcement
21	Consumers need more awareness regarding the potential harm of non-compliant biomedical products.	Consumer Safety Awareness
22	I feel that regulatory bodies should increase efforts to educate doctors and patients about biomedical product safety.	Regulatory Role
23	We struggle to maintain ethical compliance when misinformation spreads faster than facts.	Misinformation
24	I have seen cases where healthcare providers unknowingly promote non-ethical biomedical products.	Unintentional Promotion
25	I believe training programs should be mandatory for healthcare providers to ensure ethical marketing compliance.	Training Necessity
26	Our company invests in awareness, but low consumer knowledge still affects ethical sales.	Low Consumer Knowledge
27	I feel that ethical compliance is easier to achieve when doctors and consumers are well-informed.	Awareness Impact
28	We need more media campaigns to educate the public about ethical biomedical marketing.	Media Awareness
29	Many consumers do not check product authenticity because they lack basic knowledge of certifications.	Certification Ignorance
30	I have observed that higher awareness leads to better scrutiny of biomedical product marketing claims.	Ethical Scrutiny
31	We need standardized ethical marketing awareness programs across all hospitals and clinics.	Standardized Awareness
32	I think a lack of knowledge about ethical marketing creates room for exploitation by unethical marketers.	Ethical Exploitation
33	Many healthcare providers follow what their peers do without verifying ethical compliance.	Peer Influence
34	Our company has seen that ethical marketing success depends on how much awareness exists in the market.	Market Awareness
35	I believe that proper ethical training for healthcare providers can significantly reduce unethical marketing practices.	Ethical Training
36	We need stronger collaborations between healthcare institutions and regulatory bodies to improve awareness.	Collaborative Efforts

Table 6 Statistical Analysis of Awareness and Ethical Compliance in Biomedical Product Marketing

Sub-Thematic Main Key Codes	Respondent Numbers	Freq.	%
Healthcare Provider Awareness	1, 3, 4, 6, 19, 33	6	16.67%
Knowledge Gap	1	1	
Physician Awareness	3	1	
Verification Issues	4	1	
Ethical Standards Awareness	6	1	
Lack of Interest	19	1	
Peer Influence	33	1	
Consumer Knowledge and Understanding	2, 5, 11, 13, 21, 26, 29	7	19.44%
Consumer Understanding	2	1	
Product Differentiation	5	1	
Counterfeit Risk	11	1	
Consumer Negligence	13	1	
Consumer Safety Awareness	21	1	
Low Consumer Knowledge	26	1	
Certification Ignorance	29	1	
Ethical Compliance Challenges	8, 15, 18, 23, 24, 32	6	16.67%
Unethical Influence	8	1	
Exploitation of Ignorance	15	1	
Misleading Information	18	1	
Misinformation	23	1	
Unintentional Promotion	24	1	
Ethical Exploitation	32	1	
Regulatory and Institutional Role	16, 20, 22, 25, 31, 36	6	16.67%
Need for Public Awareness	16	1	
Institutional Enforcement	20	1	
Regulatory Role	22	1	
Training Necessity	25	1	
Standardized Awareness	31	1	
Collaborative Efforts	36	1	
Educational and Awareness Efforts	7, 9, 12, 28, 34, 35	6	16.67%
Educational Efforts	7	1	
Awareness Campaigns	9	1	
Hospital Training	12	1	
Media Awareness	28	1	
Market Awareness	34	1	
Ethical Training	35	1	
Impact of Awareness on Ethical Decision-Making	10, 14, 17, 27, 30	5	13.89%
Informed Decision-Making	10	1	
Price Over Quality	14	1	
Patient Trust Issues	17	1	
Awareness Impact	27	1	
Ethical Scrutiny	30	1	

Table 7 Responses on Socio-Cultural Factors and Informal Business Networks Shaping Ethical Marketing Practices

Respondent Number	Response	Thematic Key Word
1	I have observed that traditional trust-based relationships influence how biomedical products are marketed in our region.	Trust-Based Marketing
2	We often rely on informal business networks to promote products, which sometimes bypass ethical marketing standards.	Informal Business Networks
3	In our community, word-of-mouth recommendations hold more value than formal marketing, affecting ethical compliance.	Word-of-Mouth Influence
4	Many healthcare providers in our region prefer dealing with suppliers they have personal ties with, even if ethical concerns exist.	Personal Business Ties
5	We struggle with ethical marketing because local socio-cultural norms sometimes prioritize relationships over regulations.	Cultural Norms vs. Regulations
6	I feel that informal agreements between distributors and healthcare providers often dictate marketing practices more than policies.	Informal Agreements
7	Local business groups sometimes resist formal ethical marketing guidelines, making compliance difficult.	Resistance to Regulations
8	Our marketing strategies must align with cultural values, but this can sometimes conflict with ethical guidelines.	Cultural Adaptation

9	In rural areas, biomedical product marketing relies heavily on community referrals rather than standard ethical advertising.	Community Influence
10	We see that family-owned businesses in the healthcare sector tend to operate with their own informal ethical standards.	Family Business Influence
11	I think local business customs encourage flexibility in marketing, but this can lead to ethical grey areas.	Business Customs
12	In Gilgit-Baltistan, personal favors between suppliers and doctors can sometimes overshadow ethical considerations.	Favor-Based Dealings
13	We have faced cases where loyalty to a certain supplier leads to biased product recommendations.	Supplier Loyalty
14	Many healthcare businesses hesitate to adopt strict ethical guidelines because informal business networks dominate decision-making.	Informal Control
15	I feel that ethical marketing practices suffer because personal relationships often take precedence over transparency.	Relationship-Driven Marketing
16	We notice that biomedical companies must establish strong social ties before they can successfully market their products here.	Social Ties in Business
17	Our experience shows that marketing success is closely linked to how well a company integrates into local cultural practices.	Cultural Integration
18	The lack of formal oversight allows informal business networks to influence which biomedical products are promoted.	Lack of Oversight
19	I think community leaders play a crucial role in shaping the ethical marketing landscape of biomedical products.	Role of Community Leaders
20	Ethical concerns often take a backseat when informal business relationships dictate product recommendations.	Ethical Trade-offs
21	We find that informal negotiations sometimes override the need for formal compliance in marketing.	Informal Negotiations
22	Many businesses prefer using traditional networking over ethical advertising to build consumer trust.	Traditional Networking
23	In our market, trust in personal connections often replaces reliance on product certifications.	Trust Over Certification
24	Some local suppliers take advantage of informal business networks to avoid following ethical marketing rules.	Ethical Loopholes
25	We have observed that local traders prefer working with known contacts, regardless of ethical considerations.	Preference for Familiarity
26	The informal nature of transactions makes it harder to enforce ethical marketing regulations.	Transaction Informality
27	I believe informal business groups have significant power in shaping the marketing landscape of biomedical products.	Business Group Influence
28	Cultural expectations often dictate how aggressively or ethically a biomedical product is marketed.	Cultural Expectations
29	Marketing success in our region depends on social credibility rather than strict adherence to ethical standards.	Social Credibility
30	Personal networking plays a bigger role than regulatory compliance when introducing new biomedical products.	Personal Networking
31	Ethical marketing policies often remain ineffective because informal business networks hold more influence.	Weak Policy Enforcement
32	Some suppliers offer extra incentives through informal channels, making ethical compliance challenging.	Incentive-Based Marketing
33	Doctors and suppliers often engage in unofficial partnerships, shaping the marketing of biomedical products.	Unofficial Partnerships
34	We see that ethical marketing practices are harder to enforce when businesses operate primarily within close-knit social circles.	Close-Knit Business Circles
35	Local entrepreneurs sometimes adjust their marketing approach based on community preferences rather than ethical considerations.	Community-Driven Marketing
36	There is a need for balancing cultural business practices with formal ethical marketing guidelines.	Balance Between Culture & Ethics

Table 8 Sub-Thematic Main Key Codes for Q 4

Sub-Thematic Main Key Codes	Respondent Numbers	Freq.	%
Trust-Based Marketing & Relationships	1, 4, 12, 13, 15, 23, 25	7	19.44%
Informal Business Networks & Influence	2, 6, 14, 18, 21, 27	6	16.67 %
Cultural & Community Influence	3, 5, 8, 9, 16, 17, 28, 29, 35	9	25 %
Ethical Challenges & Trade-offs	10, 19, 20, 25, 32, 33, 36	7	19.44 %
Traditional & Incentive-Driven Marketing	11, 22, 26, 31, 34	5	13.89 %
Regulatory Barriers & Compliance Issues	7, 30	2	5.56 %

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THE ANOMIE OF "SMART DRUGS": ETHICAL CONTROVERSIES AND RESPONSES TO COGNITIVE ENHANCERS

Xiangyu Chen[1]

Abstract: Cognitive Enhancers (CEs) have attracted considerable attention due to their capacity to enhance cognitive performance. These agents are classified into two categories: prescription drugs and non-prescription supplements. Despite their efficacy, the potential for addiction and associated risks have given rise to numerous ethical controversies. This article explores the ethical issues of using CEs, including fairness and equality, coercion and autonomy, health and safety risks, and social norms. It proposes that the ethical issues surrounding CEs should be addressed by implementing strict supervision, promoting informed consent, improving research transparency, and encouraging multi-stakeholder collaboration. These approaches aim to achieve a balance between bio-innovation and ethical responsibility.

Keywords: cognitive enhancers, psychostimulants, addiction, drug ethics

La anomia de las "drogas inteligentes": controversias éticas y respuestas a los potenciadores cognitivos

Resumen: Los Potenciadores Cognitivos (PC) han atraído considerable atención debido a su capacidad para mejorar el rendimiento cognitivo. Estos agentes se clasifican en dos categorías: medicamentos con receta y suplementos sin receta. A pesar de su eficacia, el potencial de adicción y los riesgos asociados han dado lugar a numerosas controversias éticas. Este artículo explora las cuestiones éticas del uso de PC, incluyendo la equidad y la igualdad, la coerción y la autonomía, los riesgos para la salud y la seguridad, y las normas sociales. Propone que las cuestiones éticas en torno a los PC se aborden mediante la implementación de una supervisión estricta, la promoción del consentimiento informado, la mejora de la transparencia de la investigación y el fomento de la colaboración entre múltiples partes interesadas. Estos enfoques buscan lograr un equilibrio entre la bioinnovación y la responsabilidad ética.

Palabras clave: potenciadores cognitivos, psicoestimulantes, adicción, ética de los fármacos

A anomia das "drogas inteigentes: controvérsias éticas e respostas a intensificadores cognitivos

Resumo: Intensificadores Cognitivos têm atraído atenção considerável por sua capacidade de melhorar o desempenho cognitivo. Esses agentes são classificados em duas categorias: medicamentos que requerem prescrição e suplementos que não necessitam de receita. Apesar de sua eficácia, seu potencial para dependência e riscos associados deram lugar a numerosas controvérsias éticas. Esse artigo explora as questões éticas de usar os ICs, incluindo justiça e igualdade, coerção e autonomia, riscos à saúde e segurança, e normas sociais. Ele propões que questões éticas envolvendo Ics devem ser consideradas pela implementando uma supervisão rigorosa, promovendo o consentimento informado, melhorando a transparência das pesquisas e encorajando a colaboração de partes interessadas. Essas abordagens objetivam alcançar um melhor equilíbrio entre bio-inovação e responsabilidade ética.

Palavras-chave: intensificadores cognitivos, psico-estimulantes, dependência, ética em medicamentos

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1. Introduction

Cognitive enhancers (known as ‘Smart Drugs’) are medications designed to improve cognitive functions such as memory, attention, creativity, and motivation*(1)*. In the medical field, CEs are used to treat various conditions that impair cognitive function. Drugs such as Donepezil and Memantine are used in the treatment of Alzheimer’s disease to help improve memory and cognitive function. In addition, CEs have great potential in the treatment of other neurological disorders, such as Parkinson’s and schizophrenia*(2,3,4)*. In the real-life sphere, CEs are widely used by students and specific groups of people to boost cognitive abilities and ensure better performance in the face of stiff competition. Students commonly use these substances to improve concentration and memory in preparation for exams; specific populations use them to increase cognitive efficiency at work*(5)*. CEs currently in widespread use include Adderall, Ritalin, and Modafinil, which are prescribed for the treatment of ADHD*(6,7)*. Modafinil, methylphenidate, and amphetamine are used as stimulants to treat symptoms such as extreme daytime sleepiness, convulsions, and nighttime sleep disruptions. These stimulants can enhance consciousness, improve perception and thinking, and help maintain wakefulness*(8)*. While often overlooked, supplements such as caffeine and certain herbal extracts are widely used CEs that can improve alertness and focus.

The widespread use of CEs raises a few significant ethical challenges regarding equity, autonomy, health, and social norms, which interact with concepts such as authenticity, the good life, and the role of medicine in our lives*(9)*. To address these ethical issues, multiple parties need to be involved, which includes specific measures such as legal regulation, informed consent, transparency in research and development, and community initiatives. By promoting responsible research and use and ensuring that individuals are fully informed about their potential risks and benefits, the complexity of CEs can ultimately be better addressed.

2. Classification and application of CEs

CEs are widely used in different fields, such as medicine, academia, specific environments, and daily life. Depending on the production process and specific efficacy, CEs can be categorized into three main types: natural CEs, synthetic CEs, and prescription CEs. Relevant medical studies have shown that various types of CEs exhibit different mechanisms of action in different scenarios of use, with the four main ones being the regulation of neurotransmitters, the protection of cognitive nerves, the improvement of synaptic plasticity, and the enhancement of energy metabolism.

2.1 Class characteristics

Natural CEs are derived from natural substances such as plants, herbs, and foods; these enhancers have been used in traditional medicine for centuries and are safer with fewer side effects*(10,11)*. Synthetic CEs are artificial compounds designed to improve cognitive performance; these enhancers typically have more potent effects than natural supplements and must be subject to more rigorous research and regulation. Prescription CEs are medications prescribed by a healthcare professional for treating specific medical conditions, but are often used over the counter for cognitive enhancement. In addition to the CEs already in widespread use, there is a quiet rise in certain novel compounds that are often not approved for medical use and are used primarily in laboratory settings.

2.2 Mechanisms of action

CEs can improve cognitive function through various mechanisms, including modulation of neurotransmitters. Many CEs work by modulating the levels of neurotransmitters in the brain. Neurotransmitters such as dopamine, norepinephrine, acetylcholine, and serotonin play a key role in regulating mood, attention, memory, and learning. For example, stimulants like Adderall work by boosting dopamine and norepinephrine levels, which in turn improve attention and concentration. Similarly, donepezil, used to treat Alzheimer’s disease, improves memory and cognitive function by boosting acetylcholine levels. Second, it protects cognitive nerves. Some CEs help maintain cognitive function and prevent cognitive decline by protecting neurons from damage caused by oxidative stress, excitotoxicity, and inflammation. For example, antioxidants in ginkgo biloba protect brain cells from oxidative damage, while memantine, used to treat Alzheimer's disease, prevents excitotoxicity by blocking NMDA receptors*(12)*. Third, improving synaptic plasticity. Enhancers that improve synaptic plasticity can strengthen connections between neurons, promoting better communication and enhancing learning and memory. For example, racetams such as piracetam enhance cognitive function by improving synaptic plasticity. Fourth, it enhances energy metabolism. CEs that improve the brain's energy metabolism can increase mental energy and endurance, enhancing cognitive performance. For example, modafinil enhances energy metabolism to improve attentional alertness and cognitive function.

2.3 Status of application

Global applications of CEs vary depending on cultural, economic, regulatory, and medical factors. Overall, the current application scenarios for CEs are in three main areas: specialized medical diagnostics, academic and specific occupational needs, and daily life needs.

CEs are essential in treating various cognitive and neurological disorders in specialized medical diagnostics. In North America and Europe, Alzheimer's patients often use prescription drugs such as donepezil and memantine to improve cognitive function and quality of life. These medications help patients maintain cognitive abilities and slow the assault of the disease by increasing acetylcholine levels in the brain or blocking NMDA receptors. CEs are also being explored for the treatment of other neurological disorders, such as Parkinson's disease, schizophrenia, and traumatic brain injury, with donepezil and memantine showing great potential for alleviating cognitive deficits associated with Parkinson's disease. In addition, college students at risk for eating disorders (ED) are more likely to use CEs and psychostimulants to improve cognitive function and lose weight*(13)*. Research also suggests that certain cognitive enhancement medications may also improve cognitive function in patients with schizophrenia, although the exact mechanisms need to be further investigated.

In terms of academic and specific vocational needs, students in some areas often use CEs to improve their academic performance, and these substances help them to improve their memory, concentration, and study efficiency during exam periods*(14)*. In a survey of UK university students' use of CEs to aid their studies, participants reported a variety of motivations for using CEs, the most common being to fulfill class requirements, improve concentration, or stay awake*(15)*. For example, prescription stimulants such as Adderall and Ritalin are widely used among college students in the United States, and these drugs improve learning by increasing levels of dopamine and norepinephrine in the brain, which improves attention and concentration. However, one study showed that methylphenidate, dextroamphetamine, and modafinil resulted in a significant reduction in the knapsack value (note: a combinatorially optimized NP-complete problem) obtained in the task, even though the odds of finding the best solution (about 50%) were not significantly reduced*(16)*. CEs are equally popular in specific occupational settings, especially in high-pressure finance, technology, and law industries. Some population segments use these substances to improve concentration and cognitive acuity to cope with long work hours and high-intensity tasks. For example, caffeine products, a widely used cognitive enhancer, can be found in workplaces across the globe.

In terms of everyday needs, in addition to academic and medical uses, CEs are also used by the general population to enhance daily cognitive performance. In countries where coffee culture is prevalent, such as Brazil and Italy, consuming caffeine products is essential to daily life and work. Natural supplements, such as ginkgo biloba, Brahmi, and ginseng, are also widely used for cognitive enhancement. Ginkgo biloba improves memory and cognitive function through improved blood flow to the brain and antioxidant effects. On the other hand, Brahmi and ginseng help improve memory and reduce anxiety by supporting neurotransmitter production and reducing oxidative stress.

Finally, CEs present very different application scenarios in different cultural contexts. In Western societies, using CEs is usually for competitive advantage and self-improvement. The high-pressure academic and work environments create a need for enhanced cognitive performance. As the trend of "biohacking" grows, people are trying all kinds of smart drugs to optimize their mental and physical abilities. In Eastern societies, CEs are deeply rooted in traditional medicine and cultural practices, and herbs and natural supplements are widely accepted and used for cognitive enhancement. In China, for example, traditional Chinese medicine contains a variety of herbs believed to enhance cognitive function. Cultural acceptance has contributed to the widespread use of natural CEs.

3. Ethical controversies over CEs

Whether natural supplements, prescription drugs, or experimental drugs such as racetams, these enhancers are highly sought after for their ability to enhance mental performance. However, their ethical implications are complex and multifaceted, especially with the proliferation of new CEs. As their popularity increases, so does the urgency of addressing these ethical issues.

3.1 Fairness and equality

Fairness and equality are fundamental principles in many societies and ideals that shape policies, laws, and social norms. Although often used interchangeably, equity and equality have different meanings and implications. Equity usually refers to justice and fairness, emphasizing the equal treatment of everyone according to their circumstances, while equality focuses on providing everyone with the same opportunities and resources.

Access to CEs often depends on socioeconomic status, which creates inequality in academic and professional settings. In a statistical survey of students at three public medical schools in Riyadh, Saudi Arabia, it was found that illegal access to these (cognitive) stimulants has become easier since the level of diagnosis and treatment of ADHD has increased*(17,18)*. The fact that wealthy individuals can afford high-quality CEs and thus gain an advantage over those who cannot afford these substances exacerbates existing inequalities, as success is increasingly dependent on access to these substances rather than individual effort and ability. It has also been argued that, given that unfair advantages have become ubiquitous and generally tolerated by society, this view seems questionable*(19)*. The use of CEs in educational institutions and the workplace can create an uneven playing field, where students and professionals who use these substances may outperform their peers, not just because of higher skills or effort, but because of the help of the drugs.

3.2 Compulsory vs. autonomous

Compulsory is defined by a law, regulation, or authority that requires individuals to comply. Some social actions are obligatory, and non-compliance usually results in penalties or legal consequences. Coercive measures are usually imposed to ensure social order, safety, and public welfare. Examples include compulsory education, mandatory vaccination policies, and requirements to pay taxes. Autonomy is the voluntary choice of an individual to take actions without external coercion. These actions are driven by an individual's free will, preference, or self-interest, altruism, and are not compelled by law. Voluntary measures are often associated with personal freedom and autonomy, such as charitable donations, volunteerism, and free lifestyle choices such as diet and exercise.

In highly competitive environments, there may be implicit or explicit pressure to use CEs to perform well, as individuals may feel compelled to use these substances to keep up with their peers, even if they would not want to, shaping a coercive environment for use on the one hand, and diminishing individual autonomy on the other. For groups that have taken smart drugs, hedonic effects may be perceived as favorable when at work, whereas increased physical strength may be preferred when recreationally, suggesting that the context of intended use is essential when examining abuse liability*(20)*. Another research supports the notion that the decision to use CEs is not just an autonomous choice that occurs in isolation*(21)*. Drug manufacturers may exaggerate the efficacy of a drug based on profit considerations, thus compromising the autonomy of choice of the user, who must be fully aware of the potential risks and benefits of a particular cognitive enhancer to make an informed decision; this is difficult for the average consumer. The complexity surrounding these substances, including their short- versus long-term effects, may make it difficult for individuals to fully understand what they are consenting to, raising ethical concerns about the adequacy of the informed consent process. It has been suggested that the use of smart drugs is significantly linked to individual attitudes, with the results of an online survey of UK university students suggesting that attitudes were more favorable among those who thought smart drugs were harmless and those who thought they knew enough about how to use them safely. In contrast, perceptions of unfairness were associated with negative attitudes*(22)*.

3.3 Health and safety risks

Health and safety risks can lead to immediate injuries, chronic illnesses, and long-term health effects, affecting society's overall quality of life and increasing healthcare costs. Health and safety risks also have significant economic impacts: injuries and illnesses in the workplace can lead to reduced productivity, increased medical costs, and disputes over workers' compensation claims; environmental contamination can lead to costly cleanups, legal liabilities, and medical expenses; and accidents and injuries in the home and public places can lead to significant medical costs and loss of income.

While some CEs, such as caffeine and certain smart drug supplements, have been widely used and are considered relatively safe for short-term use, the long-term health effects of many CEs are unclear. In a survey of 1,865 college students on the prevalence of smart drug use, it was revealed that more than 300 students who expressed a desire to use some smart drug did not do so, primarily because of fear of side effects*(23)*. Prescription-type enhancers such as Adderall and Modafinil can cause insomnia, anxiety, and cardiovascular problems. Many CEs, especially stimulants, carry the risk of addiction and dependence, and the consequences of drug abuse and dependence, such as withdrawal symptoms and changes in brain chemistry, present serious ethical challenges for healthy individuals and society and require rigorous and careful ethical scrutiny to balance the risks of cognitive enhancement and addiction.

3.4 Social norms

Widespread use of CEs may lead to changes in social norms and expectations that will redefine the criteria for what is considered "normal" cognitive functioning and may marginalize those who choose not to use or are unable to use these substances. The use of CEs raises questions about human identity and authenticity, and if CEs significantly alter a person's mental abilities, this will challenge notions of self and personal achievement. There is widespread ethical debate about whether achievements achieved with CEs are as valuable or authentic as those achieved without using these substances, and there is a risk of disrupting existing norms of evaluation in society. At the level of educational epistemology, CEs may alter students' moods and behaviors, thereby distorting students', educators', and policymakers' interpretations of educational contexts*(24)*.

The legal status and regulation of CEs also vary considerably across jurisdictions, with some CEs available over the counter and others requiring a prescription or being banned altogether. Ethical issues regarding the research and development of new CEs have also been questioned, including issues related to clinical trials, the marketing of pharmaceutical agents, and the allocation of responsibilities to pharmaceutical companies, ensuring that such research is conducted on an ethical and transparent basis, which is essential for the safety and efficacy of the products, as well as for existing social norms.

4. Response to ethical controversies on CEs

Although CEs promise to improve human cognitive performance, their use raises several ethical issues. To ensure that their use is fair, equitable, and safe, it is essential to improve society's understanding of CEs and ensure that these enhancers have a positive effect on the individual and the collective through measures such as stringent regulation, equitable access, informed consent, reduction of health risks, public participation in the discussion, and transparent research practices—positive effects of these enhancers on individuals and collectives.

4.1 Promotion of legal regulation and industry self-regulation

In the United States and Canada, CEs such as Adderall, Ritalin, and Modafinil are heavily regulated, classified as controlled substances, and require a prescription from a healthcare professional. Regulation of CEs varies in European countries. In the United Kingdom, prescription stimulants are tightly controlled, but over-the-counter agents such as ginkgo biloba and Omega-3 supplements are readily available. In Germany, modafinil is used to treat episodic sleeping sickness but is also used over the counter for cognitive enhancement. The European Union is working to harmonize regulations to ensure that CEs are used safely and effectively in member states. In Asia, CEs are also regulated in very different ways. Japan and South Korea have strict regulations for prescription drugs with a focus on preventing abuse. However, using over-the-counter CEs, including traditional herbs and modern supplements, is equally prevalent. In India and China, there is a long tradition of using herbal CEs such as Brahmi and ginseng, which are widely accepted and integrated into traditional cultural practices.

Developing and promoting ethical guidelines and policies for using CEs is crucial to address ethical challenges. These guidelines should specify the circumstances under which the use of CEs is ethical and provide relevant codes of practice to prevent abuse and coercive use. Specialized ethics committees could be established in schools and workplaces to oversee the use of CEs and ensure that they meet ethical standards.

In addition, industry associations and academic groups should be actively involved in developing harmonized industry standards to promote the healthy development of the industry. Promoting legal regulation and industry self-regulation is critical to maintaining compliance, ensuring ethical standards, and fostering a sustainable and trustworthy business environment. Legal regulation provides a set of rules and standards with which the industry must comply. In contrast, industry self-regulation involves voluntary adherence to ethical guidelines and best practices that go beyond legal requirements. Governments must ensure that regulations are consistently enforced and penalties are imposed for non-compliance.

Similarly, industry associations should establish mechanisms to monitor compliance with voluntary codes of conduct, including peer review and certification programs. Overly stringent regulations can stifle innovation and impose compliance costs on the industry, while inadequate regulation can lead to unethical behavior. The balanced approach is to set clear regulatory standards while encouraging industry-led initiatives for ethical behavior, creating a dynamic regulation system by balancing regulation with flexibility, encouraging voluntary compliance, and fostering collaboration. For example, academics assess psychologists’ forums to uncover the use of CEs in the online world using web crawler technology. As part of an early-warning system, NPSfinder is helpful to provide clinicians with up-to-date information on the use of nootropics in the increasingly difficult-to-track Internet world. Nootropics medications are increasing in number and type*(25)*.

4.2 Increased sensitization to safeguard informed consent

Informed consent is rooted in the ethical principles of autonomy, respect for the individual, and justice*(26)*. It gives individuals the right to make decisions about their health and participation in research based on a clear understanding of the risks, benefits, and alternatives. Ensuring informed consent is a sign of respect for individual autonomy and self-determination, and informed consent is also a legal requirement in many jurisdictions. For example, healthcare providers and researchers must obtain informed consent before administering treatment or enrolling individuals in research, and failure to do so can lead to legal consequences, including medical malpractice claims and revocation of research authorization. Transparent and effective communication through informed consent builds trust between the patient, the participant, and the medical or research organization. When individuals feel well-informed and respected, they are more likely to have confidence in the medical or research process, which promotes better compliance and cooperation.

A robust informed consent process is essential to ensure that individuals are fully aware of the potential risks and benefits of CEs, including detailed information on short- and long-term effects, addictiveness, and ethical considerations for using these substances. Public education campaigns play an important role in enhancing the public’s right to informed consent, and these campaigns can be conducted through various channels, including television, radio, social media, and community events. They should aim to educate the public about their rights and the importance of informed consent in medical and research settings. At the same time, training medical providers and researchers in practical communication skills and cultural competence can also improve the informed consent process, and training programs should emphasize the importance of ensuring that individuals fully understand the information and feel comfortable asking questions. Of course, modern science and technology can also play an essential role in enhancing the informed consent process. For example, interactive digital platforms and mobile applications can provide information in multiple languages, offer detailed explanations through multimedia, and allow individuals to view information as they see fit. Electronic consent systems can facilitate documentation and tracking.

4.3 Promoting transparency in research and development

Transparency involves open communication of research methods, data, results, funding sources, and potential conflicts of interest. Promoting transparency in R&D is essential to maintaining scientific integrity, fostering public trust, and ensuring the reliability of research results*(27,28)*. It is important to ensure that research methods and results can be reviewed promptly and that other researchers are allowed to validate results, repeat experiments, and conduct further research based on previous work. Such openness helps to identify and correct errors, thereby advancing scientific knowledge.

Public trust in scientific research is equally critical to accepting and applying discoveries. When researchers are open about their methods, data, and funding sources, they demonstrate accountability and honesty, which fosters trust among the public, policymakers, and funding agencies. Transparent research practices help to dispel doubts and skepticism, especially in areas of public interest such as healthcare, environmental science, and technology, where transparency in R&D fosters collaboration among researchers, institutions, and industry. Open sharing of data and methods enables broader collaboration and collective problem-solving to bring about more robust and innovative solutions.

In developing CEs, it is essential to ensure that all research meets the highest standards of ethics and transparency, with full disclosure of funding sources and potential conflicts of interest. Promote open access to research results and ensure that all stakeholders, including the public, have access to up-to-date research information. Collaboration between researchers, developers, and regulators can ensure that the development and use of CEs meet public health goals and ethical standards. This collaborative approach can help create a comprehensive regulatory framework that balances innovation, safety, and ethics.

4.4 Participation of multiple actors and community initiatives

Multi-stakeholder engagement and community initiatives are essential for solving complex social, economic, and environmental problems through a collaborative approach that includes the active participation of multiple groups, such as government agencies, non-profit organizations, businesses, academic institutions, and local communities*(29,30)*. Community initiatives can create more comprehensive and practical solutions by utilizing these stakeholders' unique strengths and perspectives. Specifically, they can be categorized as follows:

First, customized solutions. Local knowledge and insights help enhance cultural resilience and advance sustainable and effective interventions, so community-based initiatives involving local stakeholders can develop solutions tailored to specific community needs and contexts. This bottom-up approach ensures that initiatives resonate with the community, increasing the likelihood of success. Second, inclusive planning. An inclusive planning process actively seeks input from all relevant stakeholders, which includes creating opportunities for participation through public consultations, workshops, and advisory committees to ensure that marginalized and underrepresented groups are included. In addressing the ethics of CEs, public debates about their ethical implications should be actively encouraged to foster a more informed and participatory society. These debates should involve stakeholders, including ethicists, scientists, policymakers, and the public, exploring different perspectives and reaching a consensus on ethical guidelines. Third, empowerment and capacity building. Participation in community initiatives empowers individuals and organizations to have a voice and a role in shaping their environments, and this empowerment enhances capacity building, whereby stakeholders can be equipped with the required skills and knowledge through training, workshops, and technical assistance. Community discussions on CEs can raise awareness and promote the normalization of relevant ethical issues while providing the necessary educational support and fostering a sense of collective responsibility for the responsible use of CEs. Fourth, partnership frameworks. Establishing a partnership framework can formalize collaboration and clarify roles, responsibilities, and expectations. Memoranda of understanding (MOUs), partnership agreements, and joint action plans can all help stakeholders align and effectively coordinate efforts. Fifth, transparent communication and testing, and evaluation. Transparent communication is vital to building trust and fostering collaboration. Regular updates, open dialog, and accessible information help keep stakeholders informed and engaged, whereas transparency also includes clarity of objectives, processes, and decision-making criteria. Ethics committees and panels should be established to review and address emerging issues related to CEs and provide ongoing guidance in addressing the ethics of CEs. Meanwhile, robust monitoring and evaluation mechanisms ensure that community initiatives remain accountable and adaptable, with regular assessments of progress, feedback loops, and impact evaluations helping to identify areas for improvement and success.

5. Conclusion

Through promoting legal regulation and industry self-regulation, increased publicity to ensure informed consent, transparency in research and development, and the participation of multiple actors and community initiatives, society can better manage and use CEs to a certain extent while ensuring ethics and safety. This will not only help protect the health of individuals and maintain social justice but also promote the sustainable development of cognitive science and drug technology. Only with concerted efforts can the potential benefits of CEs be realized while at the same time effectively addressing the ethical and health challenges they pose.

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Declaration of Interest

The author reports no conflicts of interest.
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THE ETHICAL RISKS AND REGULATIONS OF MEDICAL DIGITAL TWIN TECHNOLOGY

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Abstract: Medical digital twin technology has shown tremendous potential in personalized medicine, disease prevention and treatment optimization through real-time monitoring, simulation and prediction of individual health conditions by creating virtual models of patients. However, with the rapid development of this technology, its potential ethical issues have also attracted widespread attention. Firstly, medical digital twin technology involves collecting and processing a large amount of personal health data, and ensuring the privacy and security of this data becomes the primary concern. Secondly, the biases and unreliability generated by big data algorithms during the operation of the technology also need to be considered. Lastly, the digital gap and fairness issues generated by medical digital twin technology should not be overlooked. Therefore, in response to these ethical challenges, proposing corresponding ethical regulations becomes necessary, promoting the application of digital twin technology to enhance medical quality without infringing on patients´ legitimate rights and interests, and promoting fairness and justice in the medical field.

Keywords: medical digital twin technology, ethical risks, ethical regulations

Riesgos éticos y normativa de la tecnología médica de gemelos digitales

Resumen: La tecnología médica de gemelos digitales ha demostrado un enorme potencial en la medicina personalizada, la prevención de enfermedades, la optimización del tratamiento a través de la monitorización en tiempo real, la simulación y la predicción de las condiciones de salud individuales mediante la creación de modelos virtuales de pacientes. Sin embargo, con el rápido desarrollo de esta tecnología, sus posibles problemas éticos también han atraído una amplia atención. En primer lugar, la tecnología de gemelos digitales médicos implica la recopilación y el procesamiento de una gran cantidad de datos personales de salud, por lo que garantizar la privacidad y la seguridad de estos datos se convierte en la principal preocupación. En segundo lugar, también hay que tener en cuenta los sesgos y la falta de fiabilidad que generan los algoritmos de big data durante el funcionamiento de la tecnología. Por último, no deben pasarse por alto la brecha digital y los problemas de equidad generados por la tecnología médica de gemelos digitales. Por lo tanto, en respuesta a estos desafíos éticos, se hace necesario proponer las regulaciones éticas correspondientes, promoviendo la aplicación de la tecnología de gemelos digitales para mejorar la calidad médica sin infringir los derechos e intereses legítimos de los pacientes, promoviendo la equidad y la justicia en el ámbito médico.

Palabras clave: tecnología médica de gemelos digitales, riesgos éticos, normativa ética

Os riscos éticos e regulamentação da tecnologia de gêmeos digitais na medicina

Abstract: Tecnologia de gêmeos digitais na medicina tem demonstrado um potencial enorme na medicina personalizadas, prevenção de doenças e otimização de tratamentos através de monitoração em tempo real, simulação e predição de condições de saúde individuais por meio da criação de modelos virtuais de pacientes. Entretanto, com o rápido desenvolvimento dessa tecnologia, seus potenciais problemas éticos tem também atraído ampla atenção. Primeiramente, tecnologia de gêmeos digitais em medicina envolve coletar e processar uma grande quantidade de dados de saúde pessoa e garantir a privacidade e segurança desses dados torna-se a principal preocupação. Em segundo lugar, os viéses e falta de confiabilidade gerados por algoritmos de *big data* durante a operação da tecnologia necessitam ser considerados. Finalmente, a lacuna digital e as questões de eqüidade geradas por tecnologias de gêmeos digitais em medicina não deve ser negligenciada. Portanto, em resposta a esses desafios éticos, torna-se necessário propor regulações éticas correspondentes, promovendo a aplicação de tecnologia de gêmeos digitais para melhorar a qualidade médica sem infringir os legítimos direitos e interesses dos pacientes, e promovendo eqüidade e justiça no campo médico.

Palavras-chave: tecnologia de gêmeos digitais em medicina, riscos éticos, regulações éticas

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1. Introduction

At present, the rapid development of artificial intelligence technology is leading the intelligent transformation of society, turning the beautiful prophecy of a "digitally intelligent survival state" into a readily available reality. Digital twin technology, as a representative product of this trend, is increasingly used as a basis for scientific decision-making and practice in various fields such as industry, transportation, agriculture, and healthcare. Digital twin technology can improve production efficiency and enhance production levels by establishing industrial digital models, simulating manufacturing processes, and conducting predictive maintenance and preventive repairs on equipment. This technology can also optimize traffic systems and alleviate traffic pressure by establishing virtual traffic models and predicting traffic conditions. At the same time, it can simulate digital farming scenarios, accurately perceive agricultural production factors such as soil, farming equipment, and climate, and dynamically adjust farming processes to improve soil structure and crop quality.

The advancement of medical science is also closely related to technological development. The application of digital twin technology in the medical field can establish a virtual mapping of medical models and a real connection with patient entities, achieving a life-cycle coverage of prevention, treatment, and rehabilitation. Of course, while enjoying the benefits and convenience brought by the rapid development of medical digital technology, the ethical concerns it raises are also worth deep reflection and avoidance.

2. Medical Digital Twin Technology and Social Ethical Interests

The term "Digital Twin Technology (DT)" first emerged in the context of the digitization of 3D arterial models in 1994 and was included in the technology roadmap of the National Aeronautics and Space Administration (NASA) in 2010. However, the concept was utilized as early as the 1960s by radiologists and engineers at NASA. Radiologists employed simple model calculations to replicate the response of human tissues to radiation, while NASA engineers created systems on the ground that mirrored space systems*(1)*. The entities involved in medical digital twin technology include patient populations, hospital entities, healthcare personnel, medical equipment, data connection media, and virtual digital models*(2)*. By connecting the aforementioned entities, an individualized, lifelong patient digital twin model is ultimately constructed.

Medical digital twin technology applies digital twin technology to the medical field, creating a data model based on real patient information within a virtual medical environment, establishing a connection between the patient's data model and the physical patient, observing and analyzing the model's response to stimuli, such as the patient's feedback to new drugs or treatment plans, and providing medical guidance for prevention, treatment, and convalescence through the analysis of the patient's medical digital model. Should the potential and role of medical digital twin technology be harnessed effectively, it would bring profound value implications to human society.

Enhancing Patients' Understanding of Diseases. Medical digital twin technology can provide a broad and profound understanding of individual health conditions, playing a significant role in offering comprehensive medical protection. This technology integrates and analyzes data from various sources, including wearable devices, genetic information, and patients' medical examination reports*(3)*. This more comprehensive data integration allows doctors and patients to devise interventions and treatment measures based on individual circumstances, isolating potential health risks and ultimately improving patients' medical decision-making. The digital medical model of patients can provide real data feedback, and a robust digital infrastructure can also manage the vast flow of data.

For instance, a hospital's digital team, through digital twin technology and healthcare systems and equipment, has proposed an advanced digital medical decision-making model. This model can systematically evaluate current medical services and avoid potential medical risks, while also assisting hospitals in operating more efficiently. Moreover, medical digital twin technology also aids in tracking patients' longitudinal data, allowing healthcare providers the opportunity to analyze patients' real-time data over time. This longitudinal analysis enhances physicians' insight into patient data, thereby providing personalized prevention, treatment, and prognostic care for patients.

Promoting the development of digital clinical trials and drugs. Medical digital twin technology surpasses traditional trial methods by using virtual digital patients, no longer relying on "humans" in physical entities for drug clinical trials. Instead, this technology is integrated throughout the trial process, including patient recruitment and sample testing. By providing insights and optimizing clinical design plans, it will transform drug trials and drug development in the clinical field*(4)*. This can greatly reduce the harm and damage caused to the human body by clinical trials of drugs. Before a new drug or medical technology is introduced, it must undergo extensive animal testing and human clinical trials to test the drug or medical technology, which may harm the health of humans and animals. Moreover, the final development and application of clinical trials is a very time-consuming and complex process, with an average cycle of 6 to 15 years*(5)*.

According to a data study in the United States, it takes nearly $2.6 billion to bring a new drug from research to final approval for market launch. What's more alarming is that about 85% of drug treatments fail in the early stages of clinical trials, with only a small number of fortunate drug trials reaching the later stages of clinical trials, which only means half the battle is won. In addition, some pharmaceutical companies in the United States spend nearly $6 billion annually on recruiting trial volunteers, and the number of people who meet the criteria and are willing to serve as volunteers is very small*(6)*. Certainly, when there is a large amount of medical data available for statistical analysis and a plethora of experimental data to dissect, clinical simulation trials allow for the meticulous selection of samples for study. The introduction of this technology becomes extremely valuable when faced with limited medical data samples, and its reliability also greatly increases. In traditional clinical trials, it is challenging to address the diversity and variability of patient samples. For instance, a medical trial might involve implanting stents in patients to observe their recovery response post-implantation. Assuming the stents are implanted into digital patient models, this not only enhances the safety applied to patients but also reduces the cost of clinical trials. It is more conducive to ushering in a new era of clinical practice, bringing a brighter future for patients*(7)*.

In the near future, it will be possible to collect and analyze trial data from a population of digital patients. By categorizing these digital populations based on various customized parameters such as gender, age, and genetic makeup, these "digital humans" will be able to fully play the role of a group sample, thereby significantly improving the precision of clinical trials for drugs and medical technologies.

Medical digital twin technology, by creating a virtual digital model of the patient, enables remote monitoring and treatment of the patient. This technology can almost be said to be an innovation in the way patients enjoy medical security services. Patients can use devices such as smart wristbands, motion locators, and smart blood glucose monitors to remotely connect the physical patient with the digital model through the network, thereby obtaining timely medical assistance and avoiding delays in treatment due to distance issues. Although remote consultation and treatment methods already exist, these are mostly suitable for the treatment of chronic and mild diseases.

However, the application of digital twin technology can assess the overall health condition of the patient through the patient's symptoms and the data feedback from the digital model, thereby providing more targeted treatment plans. In the future, this technology may also increase the possibility of remote treatment of acute and severe diseases, transmitting medical data from areas with fewer resources to medical institutions in areas with more abundant resources through secure channels, providing valuable medical advice to doctors, and creating more possibilities.

In terms of remote monitoring, digital twin technology can reduce the number of patient hospitalizations and readmissions. By closely monitoring the patient's physical condition at home or in non-emergency situations, it can detect early signs of disease outbreaks or prevent the occurrence of serious disease complications promptly.

This technology is also suitable for the transition from hospital to home, ensuring the continuity of treatment and care. Through video remote connections, patients can perform self-diagnosis of digital medical conditions, increasing the enjoyment of personal rights to life and health.

With the advancement of technology, the application prospects of digital twin technology in the medical field are broad. It not only brings more accurate health management and treatment plans for patients but also brings new opportunities driven by data to the medical industry. It is expected to achieve personalized medicine, improve treatment effects, and promote the innovative development of medical care. However, the ethical issues that may arise from the use of digital twin technology also need to be addressed and resolved.

3. The Ethical Risks of Medical Digital Twin Technology

Privacy and Autonomy in Patient Data Collection. Medical digital twin technology is still in its infancy, and the ethical guidelines and regulatory frameworks for this technology are not yet fully developed. However, the primary ethical requirement for digital twin technology in the medical field is the issue of privacy and autonomy. Unlike its applications in transportation, agriculture, and urban construction, digital twin technology in healthcare requires privacy information at the level of life due to its nature. In medical digital twin technology, the Internet of Things (IoT) collects patients' personally identifiable information, health data, genetic data, and other data involving patient privacy*(8)*. Once their data is collected, it may be stored and recorded for a long time, and to continuously update the patients' health data, patient information will also be continuously collected.

For example, a patient needs to take smart pills to measure biological data such as blood pressure and heart rate, or even invasive methods are required to collect patient data. In such cases, not only does the invasive act itself pose security risks, but there is also a tendency to infringe upon the patient's privacy-protected health data.

Thus, in the process of using medical digital twin technology, issues involving patient privacy rights become apparent in two aspects: First, the over-scrutiny of patient information. When establishing a digital patient model to provide better personalized care plans for patients, it is necessary to obtain all of the patient's medical data. In this process, it is inevitable to involve the privacy that the patient wishes to protect, and the use of medical digital twin technology carries the risk of infringing on patient privacy. Second, the leakage of patient data by others. In medical digital twin technology, medical and technical entities involved may have access to patient information, and once patient data is over-scrutinized, it then faces the risk of being leaked. If this data is maliciously leaked or even maliciously obtained by third parties, it poses a greater challenge to the protection of patient privacy rights.

In medical digital twin technology, the rights to privacy and autonomy are also intertwined. The application of this technology brings significant benefits to both doctors and patients. Physicians can obtain a lot of data closely related to the patient's body through this technology, but over time, it may lead to healthcare workers and medical institutions becoming overly dependent on data for judgment, which can gradually weaken the autonomy of medical staff in assessing the patient's health condition. More importantly, as people alternate between the virtual and real worlds, it can create illusions that affect their judgment of their own body and the real world. In the clinical application of this technology, patients need to immerse themselves in the virtual experience of the "digital model" for a long time, which can also affect their perception and adaptation to the real world, posing potential psychological health risks for patients and even the crisis of disintegration of personality. In such circumstances, the autonomy of patients can be subtly weakened*(9)*. In addition, patients' level of awareness of medical digital twin technology is not high enough, which also affects the implementation of patients' autonomy rights.

Big data algorithms generate biases and unreliability. In this technology, the Internet of Things systems continuously establish training sets for patients' medical twin data, and the technology itself is also continuously iterating and updating through algorithms, striving to provide patients with the “optimal” solution. However, whether the “optimal” determined by the technical algorithm is “truly optimal” is debatable, which involves the risky decision-making resulting from the black box of machine learning algorithms*(10)*. The algorithmic black box is considered to be a process where algorithm designers transform inputs into outputs in a non-transparent manner, while the internal working principles remain unknown. Thus, the use of the algorithmic black box represents the complexity of technology, and naturally, the risks it brings are self-evident*(11)*.

Even though that artificial intelligence technology has achieved many significant breakthroughs in various fields in recent years. For example, in 2014, Facebook’s facial recognition system accuracy could reach 97.53%, almost at the human level. In the Image Net image database, the 2.99% error rate of artificial intelligence computational analysis is lower than the 5.1% error rate of humans. However, as artificial intelligence technology becomes more deeply integrated into multiple fields, the unreliability of its technology also gradually emerges. In many situations, there are computational errors, which are an inherent obstacle for any data science. Scientific and technological methods are more prone to errors than we might think, and the computation of biased data often leads to more problems.

Technologically intelligent algorithms are increasingly making important decisions for people’s lives beyond human supervision. In medical digital twin technology, the virtual data of patients relies on algorithmic calculations, and there is a risk of whether the calculations between the data model and virtual data are unreliable. If only because the patient does not fully disclose their health data, it leads to the algorithm making incorrect judgments and treatment measures. And medical staff must rely on technological algorithms to build the patient’s digital twin model and make medical diagnoses, then the unreliability of algorithmic data will also increase the health risks of patients. Even more, the pursuit of “black box” predictions and personalized care in medical digital twin technology can lead to new over-treatment*(12)*.

In the medical field, the opacity of algorithms is not limited to patients alone. When healthcare professionals rely on medical digital twin technology to provide treatment recommendations for patients, they may also be at risk due to a lack of understanding of the specific operational principles behind the technology. This uncertainty poses a potential threat to both physicians and patients. The evolution of medical digital twin technology not only aids healthcare providers in making more precise medical decisions but also involves issues of algorithmic recommendations in healthcare.

In the future, it is anticipated that individuals will have personalized digital medical models that can collect health data in real-time and potentially drive the development of individual health. For populations with specific healthcare needs, medical digital twin technology can identify their preferred health parameters, thereby assisting healthcare practitioners in devising personalized healthcare plans. This represents the positive impact of technological advancements on the healthcare industry. However, if the algorithms driving these technologies are biased, patients may be misled by the information and decisions recommended by the algorithms.

Taking medical healthcare products and devices as an example, these services may be provided to consumers under an unjust interest-driven mechanism, raising the question: Do these services truly align with the needs and desires of consumers?

The application of technology may also exacerbate the digital divide and issues of medical justice. The proliferation of medical digital twin technology may create disparities between individuals and regions. In this technology, raw data from patients, healthcare professionals, medical devices, and hospitals is key to constructing digital twin models. If these data are inaccessible to certain groups, a digital divide is created.

First, patients may not be able to access their health data, forming a digital divide at the technological access end. Second, even if patients can afford the cost of this technology, whether they can fully understand the treatment plan and the application of the technology, and whether these truly align with their interests, constitutes a digital divide at the technological usage end. Lastly, there are also disparities in the degree of access to medical digital twin technology among patients from different regions, reflecting the urban-rural digital divide.

The digital divide issues we mention essentially involve the fairness of technology distribution. Patients not only need equal opportunities to access information but also need to involve the equity in the use of technology. The introduction and popularization of any new technology come with high costs. For instance, early artificial joint technologies used to treat severe joint diseases were very expensive, but as technology advanced and production scales expanded, costs significantly decreased. Medical digital twin technology may face a similar situation. If diagnostic and treatment services of this technology are not accessible to everyone who needs them, or if they are not covered by medical insurance, the popularization of this technology may exacerbate social inequality.

Moreover, the increase in medical costs associated with the technology may also affect the fairness of health welfare distribution. For most people, especially low-income groups, the wearable devices required for the use of this technology itself represent a significant expense. If the use of this technology becomes an exclusive service for the wealthy to improve their health status or even extend their lives, then our understanding of “equality for all,” at least the notion that “all men are equal before death,” may need to be re-examined.

4. Ethical Regulation of Risks in Medical Digital Twin Technology

Medical digital twin technology, as a cutting-edge technology, inevitably raises a series of ethical issues in its application in clinical experiments. For instance, improper technical operations may impose unnecessary burdens and stress on patients. Therefore, it is necessary to rely on modern ethical principles to guide the application of technology at a macro level. Moreover, medical ethics norms reflect the moral concepts and codes of conduct of medical staff, and China’s medical ethics tradition particularly emphasizes the concepts of “people-oriented” and “the physician’s benevolence.”

However, addressing the ethical issues triggered by medical digital twin technology cannot rely solely on the efforts of patients and medical staff. It also requires supervision by ethical committees at the societal level and regulation by legislative bodies at the national level to ensure the responsible use of technology and the protection of patients’ rights and interests.

Upholding the Principle of Respect for the Autonomy and Informed Consent Rights of Patients. Regardless of how advanced medical digital twin technology may be, it is essential to adhere to the ethical principle of respect throughout all stages of the technology, especially the foundational ones. The principle of respect originates from the four principles of biomedical ethics mentioned by American ethicists Beauchamp and Childress in their 1979 work, “Principles of Biomedical Ethics.” Respect for autonomy, non-maleficence, beneficence, and justice together form the four principles of the application of bioethics. These four principles are often used as moral guidelines for resolving medical ethical issues*(13)*. The principle of respect primarily expresses recognition of an individual’s autonomy and freedom rights, that is, it acknowledges the right of autonomous individuals to hold their views, thoughts, and to act based on their values and beliefs. This principle is crucial in ensuring that patients are treated as autonomous agents capable of making their own decisions regarding their healthcare, and that they are fully informed about the procedures, risks, and benefits associated with the use of medical digital twin technology.

The principle of respect primarily conveys the recognition of an individual’s autonomy and freedom rights, which means acknowledging the right of autonomous individuals to hold their views, thoughts, and to act based on their values and beliefs*(14)*. The goal is to respect human rights and uphold dignity.

The significance of respect lies in preventing the disregard and even insult of patients’ legitimate rights. When patients are faced with choices, it is essential to uphold both their positive and negative freedoms. In the process of adhering to this principle, healthcare providers should not obstruct patients’ autonomous decision-making and actions. Even when patients have the will but lack the capacity, healthcare providers should assist in building the patients' autonomy to support their decision-making. The scope of consideration for this principle of medical ethics is broad.

In addition to respecting patients' autonomy, healthcare professionals must also respect their right to informed consent. Before making medical decisions, patients should be fully informed of all relevant information, including diagnosis, treatment options, potential risks, and expected outcomes. Medical staff must ensure that patients understand this information to obtain valid informed consent. Moreover, respecting patients' privacy and confidentiality is part of the principle of respect. Healthcare providers need to protect patients' personal health information and must not disclose it to others or institutions without the patient's consent. It is also important to respect patients' cultural and personal differences, including their religious beliefs, lifestyles, and values. Medical staff should avoid imposing their personal views on patients and strive to understand and respect their cultural and personal backgrounds.

In the context of medical digital twin technology, especially during the clinical trial phase, assessments and supervision should be conducted on the implementation of patients' autonomy and informed consent rights, ensuring that patients receive information and make decisions freely with full respect and autonomy. On the other hand, there should be active public education about this technology to guide patients to have a deep understanding of the principles and procedures of medical digital twin technology, as well as their personalized treatment and maintenance plans. This empowers patients to exercise their rights in a real-time, dynamic, and effective manner, preventing them from making inappropriate decisions due to blind faith and worship of technology, thus truly achieving autonomy in their health and well-being.

To ensure the legitimacy and effectiveness of medical digital twin technology, implementing a mechanism for algorithmic transparency is of paramount importance. As the boundaries of technological algorithms continue to expand, the issue of "black box" algorithms has garnered widespread attention. The core of the black box problem lies in the lack of transparency, and thus, the key to addressing ethical issues is to break this opacity and promote algorithmic transparency. In the field of medical digital twin technology, not only is algorithmic transparency feasible, but patients are also increasingly able to hold the application of the technology accountable and supervise it through various means.

In the medical industry driven by artificial intelligence, algorithmic transparency can provide a new perspective on the authenticity and objectivity of medical practices, while also enhancing the advantages and authority of medical institutions and healthcare professionals in the application of technology. It is important to note that both the patient entity and its digital twin, as well as the execution process of the algorithm, are in a state of constant flux. The dynamic interaction between the physical entity and the digital model is a significant characteristic of this technology, and this trend of change adds to the complexity of the algorithmic black box.

To achieve transparent algorithmic operations, strengthening the connection between the patient entity and its digital twin is an effective and viable strategy. In the future, when medical digital twin technology is widely applied, doctors may not need to face patients directly for diagnosis and treatment. Therefore, ensuring the feasibility of treatment recommendations requires healthcare professionals to base their assessments on the changes in the patient's physical condition. When a patient's health status improves due to digital twin technology, it indicates that the algorithm is trustworthy, and this trust is built on effective communication and collaboration between the patient entity and the digital model.

For example, in the process of transferring data from the patient entity to the digital model, privacy and sensitive information may be involved. This necessitates enhanced communication and collaboration between the two to ensure that data that aids in making correct algorithmic decisions is extracted while fully protecting the patient's rights and interests, and simultaneously improving the patient's understanding of data algorithms.

The real world and things within it are always changing, and if algorithmic decisions fail to take this into account, it becomes difficult to ensure the legitimacy and effectiveness of the technology, thus failing to meet the needs of patients and healthcare professionals. When the algorithmic decisions of medical digital twin technology yield positive results, they provide positive feedback to patients and healthcare professionals, which can then be applied to subsequent algorithmic decisions. This dynamic adjustment of the technology helps to enhance trust in it, reducing the uncertainty that patients may feel due to the complexity and lack of transparency of the algorithm.

Achieving fair allocation of medical resources through ethical and legal supervision. Ethics and law are both crucial measures in maintaining medical order, regulating and constraining the behavior of medical staff and patients. Firstly, ethical supervision suggestions and legal provisions should be proposed for multiple subjects of medical high-tech, such as patients, medical staff, medical institutions, and technology operation centers, especially for the directly relevant subjects of medical digital twin technology. Establish an ethics committee specifically for this technology to strengthen the ethical supervision and legal constraints on the operation of technology and data computation, clarify the responsibilities of each link and all participants, strictly carry out ethical supervision and review, avoid foreseeable risks, and safeguard the legitimate rights and interests of patients*(15)*.

Of course, the purpose of ethical supervision and legal constraints is to protect the legitimate interests and legal rights of all stakeholders. Ethics and law never favor any improper side. For instance, when applying medical digital twin technology, it can be combined with blockchain technology, which not only enhances the confidentiality of patient data but also provides a deeper level of protection for patients' human rights. Secondly, it is necessary to define the scope and extent of technology use. Establish guidelines for the operation of technology, and try to avoid invasive data collection and diagnostic treatment for patients during the implementation of this technology. At the same time, it is also important to consider potential emotional risks and minimize psychological harm to patients. Lastly, clarify the accountability mechanism through the formulation of laws and regulations. Strictly define and implement responsibilities among different subjects at various stages, such as information modeling, digital computation, and feedback of model results.

Malicious acquisition of information, algorithmic black boxes, violation of professional ethics, and contravention of social morals are strictly prohibited and severely sanctioned. In legislation, reference can be made to laws and regulations such as the Declaration of Helsinki to further refine and introduce legal provisions and institutional norms related to medical digital twin technology. The existence of ethics and law not only serves to restrain patients and medical staff but also provides a basis for the systems and actions of hospitals and governments. The participants in medical digital twin technology include not only patients and medical staff but also hospitals and governments. The economic nature of hospitals determines their economic goal of maximizing economic benefits, but the particularity of medical services also implies that hospitals must undertake the public welfare responsibility of ensuring the safety of patients' lives.

Therefore, the basis for hospital operations and philosophy is to have both economic benefits demands and the fulfillment of public welfare responsibilities, which also requires the government to ensure that hospitals fulfill their social responsibilities while obtaining economic benefits by formulating a series of policies and regulations. First, it is necessary to accelerate the construction of a national big data medical center to achieve the coordination of patient medical data. Taking medical digital twin technology as an example, it is possible to achieve the organic integration of patients' historical health data and future health data. Second, the government should coordinate the allocation of medical resources between developed and underdeveloped areas from the perspective of the macro medical market, so that all citizens, including vulnerable groups, can enjoy the right to equal treatment.

Of course, the government's construction of a unified medical security system for all is oriented towards the fairness of outcomes, with the aim of ensuring that low-income groups can also enjoy the "most universal" medical services. The promotion of the popularization and fair use of medical digital twin technology still requires the joint efforts of the government, society, hospitals, medical staff, and patients.

5. Conclusion

While medical digital twin technology holds broad prospects for future development and profound social and moral benefits, it also faces numerous pressing challenges that need to be addressed. These challenges are not only reflected in how to ensure the security of the collection and processing of a large amount of personal health data by medical digital twin technology, but also involve biases and reliability issues arising from big data algorithms during the operation of the technology. Lastly, the digital divide and issues of fairness generated within medical digital twin technology also provoke deep thought. In response to these ethical risks and challenges, it is essential to strictly adhere to medical ethical principles and relevant ethical norms to avoid them. Only by ensuring that the legitimate and reasonable rights and interests of all stakeholders in medical digital twin technology—including patients, medical institutions, developers, and policymakers— are fully protected, can its unique value in enhancing individual health management levels and promoting the overall optimization of medical services be truly realized. At the same time, the successful promotion and application of this technology also depend on a broad consensus and cooperation across society, ensuring that technological development and ethical responsibility go hand in hand, achieving a high degree of unity between individual values in the medical field and overall social benefits.

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STELARC AND THE OBSOLESCENCE OF THE BODY: (BIO) ETHICAL AND AESTHETIC CONSIDERATIONS AROUND THE WORK

Pedro Salinas Quintana[1]

Abstract: Based on the work of the Cypriot-Australian artist, Stelarc, this article examines some of the fundamental milestones of his work that postulate a potential obsolescence of the human body. Three clear moments are distinguished in the production of the artist's work that serve as an argument to explain the possible paths of the human body in the face of the irruption of technology and biotechnologies. Finally, the scope of the relation between art, science and technology is questioned from a bioethical and aesthetic perspective that reflects on the figure of the cyborg.

Keywords: body, evolutionary art, bioethics, posthumanity, technology

Stelarc y la obsolescencia del cuerpo: consideraciones (bio)éticas y estéticas en torno a la obra

Resumen: Basado en la obra del artista chipriota-australiano Stelarc, este artículo examina algunos de los hitos fundamentales de su trabajo, que postulan una potencial obsolescencia del cuerpo humano. Se distinguen tres momentos claros en la producción de la obra del artista, que sirven de argumento para explicar los posibles caminos del cuerpo humano ante la irrupción de la tecnología y las biotecnologías. Finalmente, se cuestiona el alcance de la relación entre arte, ciencia y tecnología desde una perspectiva bioética y estética que reflexiona sobre la figura del *cyborg*.

Palabras clave: cuerpo, arte evolutivo, bioética, posthumanidad, tecnología

Stelarc e a obsolescência do corpo: considerações (bio) éticas e estéticas em torno da obra

Resumo: Baseado na obra do artista cipriota-australiano, Stelarc, esse artigo examina alguns dos marcos fundamentais do seu trabalho que postulam uma obsolescência potencial do corpo humano. Distinguem-se três momentos claros na produção do artista que servem com um argumento para explicar os possíveis caminhos do corpo humano face a irrupção da tecnologia e das bio-tecnologias. Finalmente, o escopo da relação entre arte, ciência e tecnologia é questionado desde uma perspectiva bioética e estética que reflete sobre a figura do ciborgue.

Palavras-chave: corpo, arte evolutiva, bioética, pós-humanidade, tecnologia

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Introduction

> "The kingdom of men with amputated roots begins with us. The multiplied man who mixes with iron and feeds on electricity. Let's prepare the next identification of man with a motor."*(1)*

In his book, *Goodbye to the Body*, the French sociologist André Le Breton*(2)* invites us to think about the body as a means to think about the world. Largely obliterated from philosophical discourse for centuries, we could say that it is only in the nineteenth century that the body once again took center stage with Kierkegaard, Nietzsche and especially with Freud's psychoanalysis.

Even art itself has always been the bearer of images alluding to the body*(3)*, and recently with Manet's painting, we could say that it is "carnalized". The nude, used since the Quattrocento as a way to represent deities or mythological figures (especially with the female body), scandalizes a part of Parisian society with the female nudes of *Le ºDéjeuner sur l'herbe (Breakfast on the grass)*. Manet manages, in addition to proposing a powerful, self-reflective sense of art, to take the body to a new dimension of pictorial representation*(4,5)*. It scandalizes because it seems too close, too real, and its scenes portray an everyday life and an almost insolent luminosity represented on the body made flesh, which transgresses the canon of classical art.

A little over a century after Manet, performance art once again begins to question the place of the body, but now employing the body as the very basis of the work*(6)*. In the context of contemporary art, in my opinion, there is an artist of particular relevance to the discourse of which he provides us from some of his works or performances: the Cypriot-Australian engineer and artist, Stelarc. In this article, I would like to address some (bio) ethical and aesthetic questions related to the body inserted explicitly or implicitly in Stelarc's work in order to stress the relationship of the body with science, technology and the dominant economic structures in an epochal moment that some have proposed as the advent of a transhumanity or posthumanity.

The main objective of this text is to address some (bio)ethical and aesthetic issues related to the body, which are explicitly inserted in the artist's main working hypothesis: the human body is obsolete. The complementary objectives of the article are to stress the relation that exists between art, science and technology, considering it as a backdrop to an epochal moment that some theorists, such as Fukuyama or Solano, have proposed as the advent of a transhumanity or posthumanity. To achieve these objectives, we will review some of the fundamental milestones of Stelarc's career that propose the obsolescence of the human body and examine three clear moments in its production that serve as an argument to explain the possible paths of the human body in the presence of the irruption of technology and biotechnologies. Finally, the discussion on the blurred boundaries that exist between art, science and technology is concluded by reflecting on the aesthetic-narrative resource of the *cyborg* and certain art forms that, as the art psychologist Rudolf Arnheim*(7)* points out, migrate towards the bit universe.

1. "The body in suspension"

Although in recent years Stelious Arcadious has radicalized his discourse of the "obsolescence of the body" through the mechanization and digitization of his cybernetic exoskeletons, the series of "suspensions" he made in the seventies harbored a question that was philosophically quite interesting: to carry out a kind of skeptical act on everything previously conceptualized around the body. In this regard, through its performative deployment of the body, the series of "suspensions" seems to have notably anticipated the most consistent and paradoxical thesis of its future work: the obsolescence of the human body; a path of no return from the human journey towards a possible hybrid- biotechnological accession, half flesh and blood and half cables and artificial components.

In his first interventions (*Stretched Skin Suspensions*, 1976-1988), employing a series of hooks measuring five to six centimeters embedded in his skin and by virtue of his own resistance and integumentary elasticity, he remained suspended for hours, either on the shore of the Sea of Japan, in an abandoned warehouse in Sydney or inside a museum in Krakow*(8)*. In *Event for Rock Suspen-*

sion (Japan, 1980), which in my opinion was the most impactful intervention during this period, Stelarc set out to float in space, grasped by seventeen hooks placed directly on his skin, counterbalancing his naked body with seventeen regular-sized stones (Figure 1). The remarkable visual effect of this performance (much better achieved aesthetically than the previous ones) seemed to paraphrase in some sense the title of Milan Kundera's novel, *The Unbearable Lightness of Being(9)*, which in one of its passages strips the body down to a functionality that seems to emerge from the most heinous organic mechanisticity:

> "Today, of course, the body is not unknown: we know that what beats inside the chest is the heart and that the nose is the tip of a hose protruding from the body to carry oxygen to the lungs. The face is nothing more than a kind of dashboard from which all the mechanisms of the body flow: digestion, sight, hearing, breathing, thinking (...)"*(9, p.20)*.

The naked body of Arcadious levitating, supported by invisible threads and surrounded by floating stones, now appears to us not only as a wretched challenge to gravity but also to every attribute of traditional aesthetic representation of the body. It is an ironic exercise towards its possible metaphysical dimension: a display of floating flesh that for some could be as terrifying as it is disconcerting.

2. "The obsolete body"

Over time, Stelarc's interventions on his own naked body would give way to the unregulated use of technology, allowing himself to be widely fascinated by the mechanization of the body. As an example, *The Third Hand* (Figure 2) exemplifies a new productive period; yet, this time it appears more akin to sci-art than to performance, deploying a protean hand manufactured in Japan that increases its organic potential by controlling an artificial arm attached to his body through the electrical stimuli of abdominal and leg muscles and simultaneously emitting sounds through an electronic interface*(10)*.

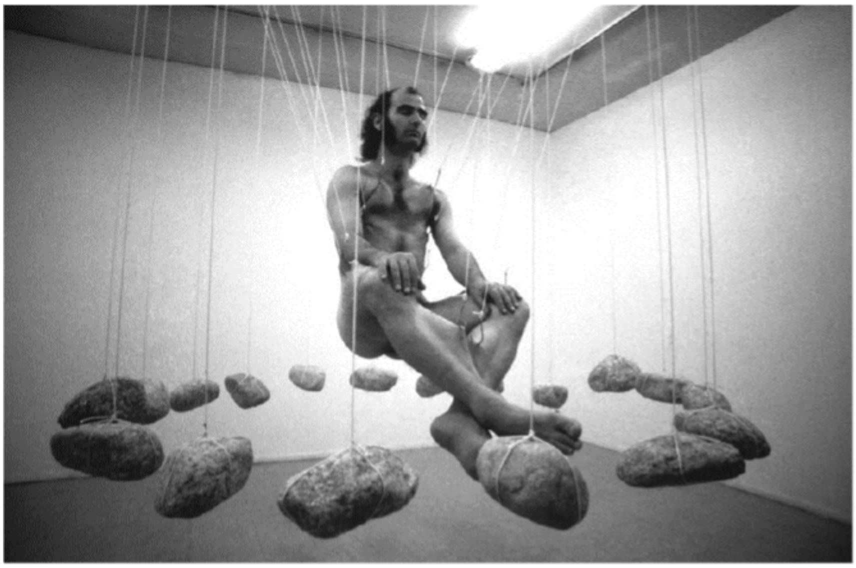

Figure 1. Stelarc – *Event for Rock Suspension* (1980). Source: www.stelarc.org

Figure 2. Stelarc - *Evolution* (1982). Source: www.stelarc.org

How can we then understand the emergence of a posthuman art through Stelarc´s example and art forms that integrate the prosthetic dimension in performance? David Le Breton, in this regard, points out the following:

"Stelarc radicalizes the obsolescence of the body, its abandonment of the species and its insignificance in the face of current technologies. For him, as for many other contemporaries, this is a kind of anachronistic shell from which it is urgent to break free. Mortification, the transformation of pure material, is a preliminary stage before its elimination or the necessary fusion of a remnant of flesh with the techniques of computer science... man's physiological structure determines his relationship with the world: by modifying it, man modifies the world. The obsolescence of the body ratifies the conditions of subjectivity (...)"*(2).*

The author adds that for Stelarc, "the body no longer seems to be the place of the subject, but rather another object of its environment"*(2, p.54)*. In this sense, the evolutionary perspective of the body and life seems to have exhausted its function at the precise moment when the human being is emancipated from and autonomized in their evolutionary need through technology that incessantly invades, supplies, or complements the body and restructures it according to distinct circumstances. Regarding Stelarc and his work, Mark Dery postulates that "[it seems that for Stelarc] the body is no longer able to accumulate the amount of information that circulates, always referring 'to the body' and not to his body"*(2, p.54)*.

However, Stelarc's concern, at times, does not even allude to a "terrestrial" body. Rather, his discourse moves towards what seems to him to be the inescapable adaptation needs to the outer space of the humanity of the future:

"[The body] cannot cope with the quantity, complexity and quality of information... it is intimidated by the precision, speed and power of technology and is biologically ill-equipped to cope with its new extraterrestrial environment"*(10)*.

With this, the ancient Greek notion of *bios* as a place of reference to the nature of the terrestrial world is lost, and once its physical possibilities are exhausted and then artificially reestablished, "life", the "living" and the "living being" will accept the possibilities of differentiated ontological domains of a human-organic body and a hybrid-artificial-extraterrestrial body.

3. "The body colonized by technology"

Similarly to Arnold Gehlen´s thought at the time, Stelarc affirms that the idea of humanity has been radically modified by technology, which replaces, supplements or complements physiological functions (technoevolution) and progressively abandons a tissue-based biology and the original organic component. This separation of the body and its organic biological dimension from its counterpart of technological intervention is a dyadic blueprint that creates tension and juxtaposes the realm of the "living" and the "living being",

Figure 3. Stelarc – *Exoskeleton* (2003-2011). Source: www.stelarc.org

thus producing a quality relative to the organic in the former and, in the latter, a quality to be defined, yet open to the possibilities of a hybrid or a completely mechanized-virtual way of life. As such, the enhancing or supplementary artificiality of the human body, with its implants, extensions and possibilities of representation, is probably defined as a post-biological category given that it will claim its own existence, as in the case of the replicant in *Blade Runner*.

Therefore, humanity – reified, protean and permanently interconnected to a computer or a server – becomes cybernetic humanity, as Le Breton*(2)* points out, at which time the body is physiologically, electronically and virtually colonized by technology. As in Putnam's philosophical experiment in *Brain in the Pan* in which a brain connected to a super computer feels, lives and experiences the belief of being an embodied human body, Stelarc's work leads us to consider how the biological body will be able to maintain its relationship with attributes, such as the "organic" and the "artificial", with the irruption of a virtual-digital world. Dery points out that "the physiological structure of the body determines its intelligence and its sensations, and if you modify that [structure], you get an altered perception of reality"*(11)*.

That is why when the artist-engineer considers the body "obsolete", this assumption opens up the possibility to the *summum* of technological madness or to the noblest of human achievements*(12)*. However, for the artist today, understanding corporeality as the core of the psyche or the social realm is meaningless*(12)*. His suggestion would then seem to comprehend the body more precisely as a structure that can be controlled and modified, such as a computer or, as I propose, as a *portable information device* that will

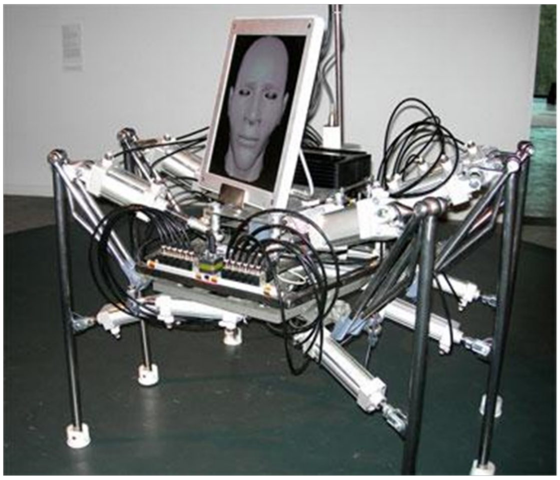

Figure 4. Stelarc – *Walking Head* (2001-2006). Source: www.stelarc.org

accept a series of transient couplings with other devices, with a floating identity, and is permanently updated with the incoming data to your nervous system: "evolution ends when technology invades the body. The body not as a subject, but as an object, not as an object of desire but as an object of design"*(11)*.

In response to the author's *technoperformatic* display, Le Breton concludes that the body is now an alter ego from which sensations and emotions emanate:

"A geometric place of the reconquest of oneself or territory to be explored with vigilance for unprecedented sensations. A social and economic asset that must be modeled to seduce and obtain the approval of others. A body, whose sudden passion for itself, is a consequence of the individualistic structuring of our Western societies, especially in its narcissistic phase"*(2)*.

For Vilém Flusser, the reformulation of the *ars vivendi* of (the convergence of telematics with biotechnical biotechnology) predicts the resurgence of the oldest conception of art of Latin origin, which is understood as "the art of life or knowing how to live." It projects the possibility that life can now be programmed at its most fundamental level: the genetic level. Where here the arts, which until now, were limited to the more or less complex manipulation of inanimate matter, they now face the extraordinary and terrifying novelty that it is possible to elaborate information, imprint it on living matter and thus multiply and preserve this information.

"It is necessary that the artists participate in the adventure. The challenge is obvious: we currently have a technique (art) capable not only of creating new living beings but also life forms with new mental processes ("spirits"). We currently have the technique (art) suitable for creating something hitherto unforeseen and unimaginable: a new living spirit. This spirit is the creator itself and thus will not be able to understand since it will be based on genetic information that is ours. This is not a task for biotechnicians immersed in their own discipline, but rather a task for artists who collaborate with the currently established laboratories (...)"*(13)*.

Faced with this scope of possibilities, some artists, such as Eduardo Kàc (14) and his transgenic art, propose to raise the banner of the contemporary artist to dispute the biotechnology of the possible supremacy of the use of technique and technicians – an aspect that assumes the most radical discontinuity of art from its tradition by no longer producing inert images but rather creating living works.

4. Some philosophical considerations: the fascination of technique

From an empirical-anthropological-philosophy perspective, Arnold Gehlen considered technical dominance as a threat to culture and individual personality, projecting, similarly to Paul Virilio*(15)*, a mass, standardized and manipulated society. He considered that, ultimately, the Modernity technique is the result of the "will to impose oneself", and consequently, all modernity, that is in its technical essence, makes man a "technical functionary", as termed by Heidegger, one of the thinkers who emphasizes a philosophical reflection on the purely instrumental use of technique, as well as the disturbance in the human-nature relationship.

What is truly disturbing is not that the world is turning into a complete technical domain. Far more disturbing is that man is not in fact ready for this radical transformation of the world. Far more disturbing is that we are not yet prepared of reaching, through meditative thought, an adequate confrontation with what is emerging in our time*(16)*[2].

In relation to human nature, Gehlen*(17)* considers that there is a natural and innate impulse in the human being that made his adaptation and survival in nature possible: a creative faculty strengthened – in addition, by the endowment of "artistic wisdom" that Plato points out – in conjunction with a genetic inheritance and "spiritual equipment" for the development of artifacts or utensils. And, since the human being did not have an instinctive skill or organs that advantageously disposed him to deal with nature, as in the case of animals, the human being as *Mängelwesen* (a "being with deficiencies" or

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[2] This translation is my own.

"lacking being", a concept previously present in Herder) achieves its survival by replacing, complementing or strengthening the organic through the intellect. This early human fascination with technique, which Gehlen*(17)* describes from an anthropological perspective, was interpreted by Ernst Kapp*(18)* as an interest in achieving "*organ projection*", similar to Stelarc with his "Third hand" or "Third ear". From Kapp's perspective in which the technique has been "embodied" in the human body waiting to be deployed by the needs of the environment:

"The wealth of spiritual creations springs, then, from the hand, the arm and the teeth. A bent finger becomes a hook, the hollow of the hand a plate; in the sword, the spear, the oar, the shovel, the rake, the plow and the spade, various positions of the arm, hand and fingers are observed, whose adaptation to hunting, fishing, gardening and farm implements is easily visible"*(18)*.

But from this perspective, the instruments and tools of the technical world developed by the human being not only reproduce the possibilities of the organic world but also allow their creator to return to nature with increased power over the world and therein lies part of its greatness and potential danger. In this regard, Gehlen points out that the "projection of organs" extends to the possibility of covering three basic functions: "organ replacement" (*Organersatz*), "organ discharge" (*Organentlastung*) and "organ overcoming" (*Organuberbietung*):

"The stone in the hand to strike both discharges and successfully overcomes the striking fist; the cart [and] the riding animal relieve us of the movement on foot and far exceed their capacity. In the pack animal the principle of unloading becomes evidently clear. The plane, once again, replaces our wings that have not grown and far exceeds all organic capacity for flight. Some of these examples indicate that there is a very old technique of the organic: domestication, especially animal husbandry, is a genuine technique that only succeeds after many experiments"*(17, p.114)*.

It could be thought, then, that in any case the human being develops a technique that substantially participates in nature. However, when the work of mastery over nature is undertaken – what we could consider the essence of the Baconian ideology of modernity – it would be the moment that risks the radical autonomy of the technique, along with the prevalence of the object. Galimberti*(19)* thinks that the essence of the technique is obscured because modern sciences are not capable of thinking about the foundation of their own development.

The complete realization of the Baconian formula has brought about a profound transformation in the narrative. It no longer revolves around the supremacy of humans over nature; instead, it underscores the ascendancy of technology, exerting control not only over human beings but also over the natural world. This shift signifies a redefined power dynamic, where the influence once wielded by humans is eclipsed by the overwhelming force and impact of technology on both humanity and the environment*(19)*.

In relation to this, Heidegger*(16)* argues that technology is a mode of understanding the world, where entities are technically uncovered and disclosed. Furthermore, Heidegger aims to delineate the specific nature of modern technology, distinguishing it from Greek technology. He also underscores the ambiguity and danger that modern technology poses for humans, revealing a destiny that emerges from Being itself and implying the loss of self-awareness and a reduction in human freedom. Paraphrasing Heidegger*(16)*, he later points out how in this context, observing the human being reduced to a "technical functionary" is akin to the human being being "elsewhere" in relation to the dwelling they historically knew; hence, it signifies being "far from oneself." In this manner, the distinction between fact and value implies that technology, along with science, is capable of instructing us "how" to carry out something, irrespective of whether this is significant in relation to the appreciation of the common good, or even more so, if this implication of technical development involves a reflective questioning about the scope and implications of this or that scientific innovation. For this reason, the technification of existence can in no way be seen as something "neutral."

Where then do we find the essence of the technical and its formative implications for culture?

For now, we can clearly say that one is probably in the encounter between aesthetics and ethics, but according to Galimberti (19), ethics shows its impotence in the contemporary world due to a predominance of technique and a world regulated by doing as the pure production of results in which the effects add up in such a way that the final successes are no longer compatible with the intentions of the initial agents. This means that it is no longer ethics that chooses the ends and that is supported by technique to find the means, but rather it is technique that, assuming the results of its procedures as ends, conditions ethics, thus forcing it to take a position on a denatured or artificial reality in which the technique does not cease to build, produce and permit the object according to whatever its position assumed by ethics.

5. Conclusions: "This reminds me of a story..."

Considering the artistic sphere of recent years and with regard to the numerous intersections between art, science and technology, certain artistic creations consider the biological body, its limits, scopes and technological extensions in relation to a "humanist" project an openly disputed territory. In this regard, the promoter of transgenic art points out that new technologies culturally alter our perception of the human body, which ranges from being a naturally self-regulated system to an artificially controlled and electronically transformed object*(14)*.

From an artistic perspective, filmmaker David Cronenberg, for instance, has explored the concept of the "New Flesh." In his interpretation, it becomes an integral part of the organic-machine synthesis, giving rise not to a combination of flesh and metal but rather to flesh transformed through the machine's influence — a futuristic embodiment resulting from an almost sensual interaction with the technological realm. The "New Flesh" represents a psychophysiological transcendence of the conventional notion of subjectivity, disrupting the dualistic framework that separates mind and body. In this context, the "New Flesh" is conceived as a psychophysiological overcoming of the classical idea of subjectivity, challenging the dualistic structure that distinguishes between mind and body*(20)*.

In consideration, the concept of *posthumanity* has been a concept that has perhaps incorporated a greater number of critical elements to be presented as the last link in the chain of biotechnological advances that are situated at the core of the contemporary scientific-social imaginary. Likewise, the concept of *posthumanity* is installed in a broad framework of discussion that ranges from the possibilities to the dangers associated with the use of biotechnologies in everyday life and their effects. This framework considers two concepts proposed by bioethics that describe the relations between humanity and its association with new technologies in terms of biological alteration, which is necessary to differentiate: the *transhuman* and the *posthuman*. To address this distinction, Póstigo Solana argues that "the first would be a human being in transformation, with some of their physical and psychic abilities being superior to those of a 'normal' human being, but not yet 'posthuman'"*(21)*. On the other hand, a *posthuman* subject would be considered a being (it is not specified whether natural or artificial) that the author describes with the following characteristics: a life expectancy of more than 500 years; intellectual abilities two times greater than the maximum that the current human being could have; and mastery and control of the impulses of the senses, without psychological suffering*(21)*. Such provisions of biotechnological superiority would eliminate any ambiguity between the human being and the posthuman.

Among the critics of this concept, Francis Fukuyama, one of the theorists who has contributed the most in arguing the possible *posthumanity* and its consequences, warned in *Our Posthuman Future* about a dangerously near future in which the distinction between therapeutic improvement and ethics will fade. According to the author, it is impossible to not associate this progression with the inevitable super-commercialization of life, which this probable future will implicate*(22)*. In this sense, Fukuyama's concern is related to the possibility that a commercial model of biotechnology could surpass existing medical ethics based on humanitarian concerns. With regard to this, he mentions that:

Human nature shapes and restricts the possible types of political regimes, but with a sufficiently powerful technology, it would be enough to reshape who we are, with possible malignant consequences for liberal democracy and the nature of politics in themselves*(22, p.7)*.

The author, taking into account these assessments, defends the existence of a fixed concept of "the human" or "humanity" as an essential term for social organization*(22)*, a term that reaffirms the fundamental values of humanism over the new technological and ethical possibilities that the development of science brings forth.

In this regard, Paul Virilio points out that if the human body, inherited and natural, has become obsolete, it is due to the installation of the *fragmented body* (*post-industrial*), which as he understands, developed in parallel to the brutal strengthening of the omniscient tele-visions, which have produced "a disregard for the dimensions of the body itself"*(15)*. Stelarc, meanwhile, after his initial *suspensions*, would progressively radicalize his thesis of the obsolescence of the body through consecutive technoperformatic exhibitions until arriving at a digital modeling of himself whose destiny is a screening of his artificially simulated face in the center of a *cybernetic mechanized exoskeleton*, an aspect that largely resembles a kind of *post-human antihero*.

This "new flesh" could be understood as the symbiosis that, in representational terms, has taken on the form of the *Cyborg's*[3] *postbody(23)*: an entity, neither completely human, nor completely machine, endowed with a singular self-consciousness, as reflected in the closing dialogue of the film *Blade Runner* by Ridley Scott, in which Roy Batty - Nexus 6 (Ruter Hauer), one of the *cyborg replicants* with superhuman capabilities, decides to save Deckard (Harrison Ford), his pursuer:

It's quite an experience to live in fear, isn't it?

That's what it means to be a slave.

I have seen things that you would not believe.

Attacking burning ships beyond Orion

I've seen C-rays glow in the dark,

near the Tannhäuser Gate.

All those moments will be lost in time,

like tears in the rain (...)*(24)*.

Within this context, the Cyborg's elevation to an aesthetic category symbolizing the new flesh proves to be a fruitful instrument for philosophical exploration. It is also employed as a resource in discussions pertaining to gender and feminism*(25)*. This representation scheme concurrently addresses both dimensions, symbolizing the concept's permeability and cultural universality.

Concerning the connection between art and bioethics, MacNeill*(26)* proposes that bioethics could gain valuable insights by welcoming contributions from the arts, particularly from artists who explore materials, including their own bodies, at the nuanced intersections of art, bio art, and bioethics. These artists aim to involve audiences in questioning ethical principles and assumptions related to life and existence. As noted by MacNeill*(26)*, the 2008 Croatian Congress on Art and Bioethics serves as an illustration of this potential collaboration

According to Hubenko*(27)*, the interdisciplinary interplay between bioethics and art has the potential to reshape the methods and channels through which art is shared amid emerging biotechnological advancements. Simultaneously, these two disciplines contribute to a critical examination of the role of science and its responsibilities in the contemporary world. Bioethics, in this regard, can contribute to the socialization of art, and conversely, art can serve to popularize the subject matter studied within bioethics.

However, and in consideration of the above, it seems to me that the intersection between science, art, technology and bioethics will reach a high point of discussion when the machines demonstrate some degree of self-awareness. In such

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[3] The term *Cyborg* "cybernetic organism" was coined in the 1960s to describe the fusion of technology with the human body. Manfred Clynes and Nathan Kline, both NASA scientists whose perspective was to strengthen the human body for long and challenging space travel, seem to be the proponents of the term. The researchers proposed the combination of chemical substances and technological surgery (body implants based on the operation of computers), along with other faculties enhanced by expert electronic systems coupled to the body.

instances, the authentic exploration and transcendence of human limitations through machines do not solely hinge on the technical achievement of replicating a flesh-and-blood human body, as exemplified by the replicants in Blade Runner. While this technological feat is undoubtedly underway and already in progress, the authentic philosophical inquiry arises when these entities achieve the most enigmatic of attributes, surpassing even the capabilities of advanced neuroscience: consciousness and inherent self-awareness. This critical juncture represents a distinct turning point, prompting a profound exploration into questions concerning the nature of consciousness. To exemplify this perspective, in the 1960s, biologist Gregory Bateson*(28)*, reflecting on the components and qualities of life amid the burgeoning era of computer technology, recounted a poignant narrative to his students at a California art school. This narrative aimed to clarify what he perceived as the fundamental essence of the human phenomenon:

A man wanted to know something about the spirit, finding the answer not in nature, but on his large private computer. He asked the computer (no doubt in his best Fortran language), "Do you calculate that you will ever think like a human being?" The machine then went to work to analyze its own computing habits. Finally, the computer printed its answer on a piece of paper, as machines usually do. The man ran towards the answer and found these words clearly printed:

…THIS REMINDS ME OF A STORY... (...) *(28, p.21)*.

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OBSERVACIONES SOBRE “PRINCIPIOS DE ÉTICA BIOMÉDICA”

BEAUCHAMP, T. L., CHILDRESS, J. F.
Principios de Ética Biomédica.
Traducción al español, estudio introductorio y notas de Erick Valdés.
Universidad Pontificia Comillas, Madrid, 2024.
(ISBN 978-84-7399-162-9), 694 págs

Fernando Lolas Stepke[1]

El libro de T. Beauchamp y J. Childress es texto canónico de la versión *medicalizante* de lo que en el década de 1970 empezó a llamarse “bioética”. Sus ocho ediciones en inglés (la primera de 1979, poco después de publicado el Informe Belmont) y su influencia en numerosos ámbitos prueban su amplia difusión e impacto. La traducción del profesor Erick Valdés es cuidadosa y abunda en notas explicativas que harán de este libro referencia indispensable en el mundo hispanohablante.

Para Paul Ricoeur lo ético es intencionalidad hacia la “vida buena”. Se manifiesta en “juegos de lenguaje” que *justifican* usos morales derivados de la tradición, la costumbre y la razón. Hans-Georg Gadamer decía que una postura ética consiste en creer que, de buena fe, otras personas también pueden tener razón. Hay en los discursos éticos una vertiente aspiracional que obliga a distinguir entre *ideales morales* y lo *justificable* en teoría y práctica. Este punto recibe adecuado tratamiento en esta versión, que es referencia esencial para orientar decisiones y acciones de los profesionales sanitarios. El epítome “ética biomédica” ilustra una tendencia integradora que no debiera ignorar la constitución polifónica (de muchas voces) del oficio de curar, sanar y acompañar que constituye lo médico.

La práctica deliberativa que instaló el discurso bioético se manifestó por la creación de instituciones sociales (comisiones y comités); el diálogo se hizo fundamento para tomar decisiones en situaciones de incertidumbre o frente a dilemas planteados por la irrupción de la técnica en los asuntos humanos a una escala sin precedentes. Este libro ha servido como guía para comités de ética asistencial y de investigación, y sus cuatro principios fundamentales reciben en esta edición especificaciones adecuadas, ejemplos de aplicación razonada y aclaración sobre malentendidos debidos a lectores apresurados o prejuiciados. Uno notable, expresamente aludido, se refiere a la preeminencia que parecía asignarse al principio de respeto por la autonomía, interpretable como sesgo cultural y que parecía contradecir prácticas habituales en muchas regiones. Cuando generábamos debates en la unidad de bioética de la Organización Panamericana de la Salud (OPS) solíamos encontrar una acentuación de la equidad (entendida como justicia distributiva) entre los participantes iberoamericanos.

No es posible discutir en profundidad los conceptos nucleares de la tradición que este libro inaugurara, usualmente aludida bajo el polisémico término “principialismo”. El “mantra de Georgetown”, como suele denominarse la tétrada autonomía-no maleficencia-beneficencia-justicia, ha sido objeto de críticas, elogios, abusos e incomprensiones. Asuntos como la primacía de un principio sobre otros, dificultades en la especificación y ponderación de los principios, dudas sobre su relevancia en algunos ámbitos prácticos, colisiones con teorías éticas que destacan las virtudes o el casuismo,

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dudas sobre su adecuación a algunas situaciones y la posible ampliación de su número con otros como solidaridad, reciprocidad o vulnerabilidad mantendrían ocupados por semanas a grupos de personas. Los "momentos" deontológicos y teleológicos están siempre presentes en las discusiones cotidianas y en las deliberaciones ilustradas.

Esta edición incorpora discusiones sobre temas y perspectivas que antes no recibieron igual tratamiento. En lo relativo a las virtudes y al estatus moral hay interesantes disquisiciones, adecuadamente traducidas y comentadas. Como es habitual en textos estadounidenses, la mención de bibliografía publicada en otros idiomas y no traducida al inglés es escasa. En relación al estatus moral, la discusión sobre otros seres vivos o personas incompetentes o discapacitadas será sin duda de gran valor en las deliberaciones. El clásico de F. J. Buytendijk *Mensch und Tier* anticipaba algunos temas sobre la relación entre seres humanos y animales. Recordando a Fritz Jahr y su formulación del imperativo bioético en los años 20 del siglo pasado, no sobra insistir que la vida en general recibía en sus escritos un estatus moral hipotético, no categórico, que invitaba a un análisis diferenciado de contextos y circunstancias.

Un tema que preocupó a los primeros "usuarios" de este marco referencial se refería a la prelación o importancia relativa de los principios. Diego Gracia, entre otros, propuso una suerte de estratificación de ellos basada en las nociones de moral de mínimos y moral de máximos. Esto se aplica de manera importante a las discusiones sobre la beneficencia y sus relaciones con la no-maleficencia (de ésta hace Gracia fundamento de toda moral médica en su discurso de ingreso a la Real Academia de Ciencias Sociales y Políticas). Un detalle que no debiera ignorarse es la alusión a la reciprocidad en el contexto de la beneficencia, pues este marco referencial —a diferencia de otros— no releva la *reciprocidad* como principio independiente. Escasa mención recibe la *solidaridad*, que en la medicina antropológica alemana ocupa un lugar. Baste recordar el artículo de Viktor von Weizsäcker de 1947 en el cual, a propósito del juicio de Nüremberg, se explaya sobre la *Gegenseitigkeit* y la *Solidarität*. La adecuada especificación y ponderación de los principios, considerando contexto y circunstancias, bastaría para abordar casos complejos y realizar la que parece ser meta de la deliberación: tomar decisiones prudentes. Más allá de esta loable y práctica utilidad, el sistema conceptual está diseñado más para resolver dilemas y conflictos que para anticiparlos, aunque la lectura de este libro proporciona herramientas para ello. Una "ética anticipatoria" es necesaria y suele condensarse en protocolos y normas procedimentales que obviamente no pueden prever todos los escenarios posibles en el sistema social de cuidado y promoción de la salud. El "aggiornamento" de la reflexión debe considerar el impacto del cambio experimentado por las tecnociencias. Los pasajes relacionados con la autonomía, la beneficencia y la objeción de conciencia recuerdan que una práctica diádica (o multidiádica), como la que caracteriza a las "profesiones éticas", no debe olvidar que los practicantes de los oficios también gozan de autonomía y que una contrastación "axiográfica" entre los participantes es imperativa. La sugerencia de Hans-Martin Sass de un "axiograma" que pudiera ingresarse a la historia clínica (al igual que hemograma, electrocardiograma, etc.) y la propuesta del padre Alfonso Llano de una "objeción de conciencia institucional" merecen discusión (más allá de cualquier precisión jurídica).

La tensión cotidiana entre beneficencia (incluso concebida en el sentido de un "paternalismo libertario") y autonomía recuerda los aforismos clásicos: "*Aegroti voluntas suprema lex*", que se contrapone a "*Aegroti salus suprema lex*". El segundo supone que la "*salus*" del "*infirmus*" es materia de quienes saben y tienen poder sobre otros en virtud de la "verticalidad" profesional (versados versus legos), que la práctica bioética ha "horizontalizado" en versiones contractualistas y compasivas. La discusión que este libro promueve sobre la empatía y la simpatía no debe olvidar lo que el gran clínico William Osler, Regius Professor en Oxford, destacaba como virtud cardinal: la "*aequanimitas*". La ecuanimidad es una suerte de distancia compasiva que permite ejercer el oficio sin sentirse obnubilado por emociones y compasión. De nuevo aquí hay una fructífera posibilidad de discutir sobre virtudes, competencia técnica y juicio con discernimiento moral.

Bastante habría que decir sobre la idea de “moral común” que subyace a esta obra. Los principios “*prima facie*” son acertadas orientaciones para una práctica en continua evolución, moldeada y amenazada por contextos institucionales y jurídicos en constante cambio. Tal vez el éxito de un libro como este resida y seguirá residiendo en la posibilidad de interpretaciones múltiples. Conllevan éstas el riesgo de una trivialización pero prometen una flexibilidad adaptativa a diversos entornos.

Encomiable es la cuidadosa traducción. Al examinar términos y usos lingüísticos adaptables a la lengua española previene apresuradas críticas y malentendidos. La nota introductoria es tanto una razonada exposición como una defensa del marco conceptual que caracteriza a este libro. Refuerza la idea de que el debate moral nunca se cierra y que la construcción de nociones y prácticas es tarea permanente.

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