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INVESTIGACIÓN EN EL CONTEXTO UNIVERSITARIO. NECESIDAD DE UNA ÉTICA INSTITUCIONAL

Fernando Lolas Stepke[1]

El contexto universitario ofrece particularidades que deben examinarse para evaluar conflictos éticos en la función investigativa. Ésta no es homogénea. Difieren sus supuestos, las motivaciones de diferentes agentes y actores, las disciplinas, sus productos y los *contextos* en que se realiza. Siempre implica renovación conceptual y humana de las disciplinas intelectuales.

La voz investigación tiene diversas connotaciones según el idioma. *Ricerca, recherche, research*, *Forschung*, aunque reducibles a una matriz común, tienen acepciones que cada lengua privilegia con diferente amplitud temática y metódica.

Investigación se realiza en universidades, academias, industria, asociaciones gremiales o profesionales, incluso privadamente. En cada espacio imperan culturas epistémicas distintas; por tanto la sociología del conocimiento, explícito e implícito, que determina autoridad, validez y confiabilidad puede diferir.

Recordemos la *pirámide epistémica*: datos – información – conocimiento – sabiduría, con sus respectivos significados. Las informaciones son datos formulados mediante una teoría de medición o expresión. El conocimiento es organización y arquitectura de informaciones. Sabiduría incluye prudencia, conocimiento de cómo usar el conocimiento (fines últimos de la cultura global).

Los productos del proceso investigativo son *Invención* conceptual, *Innovación* de prácticas y *Transformación* individual, institucional y social. Se asocian a motivaciones de distintos agentes y actores. La invención produce nuevos "*inputs*" para el sistema conceptual (investigación básica o fundamental). La innovación busca nuevos "*outputs*" para conceptos conocidos. La transformación depende del impacto del conocimiento en personas, instituciones y sociedad.

Habría que discernir entre distintos tipos de universidad; el término es polisémico. La universidad moderna debe mucho a Wilhelm von Humboldt; al fundar la Universidad de Berlín, en 1810, pensó en la *unidad de enseñanza e investigación*. Los miembros académicos recibían pago por enseñar y podían cultivar sus inclinaciones intelectuales libremente. La clásica universidad europea tenía "facultades mayores" de Teología, Medicina y Derecho; el conocimiento y las formas de su incremento o perfección eran distintas en ellas. La idea de que ha de buscarse lo novedoso o lo nuevo es distinta en las disciplinas que reinventan el pasado o privilegian la imaginación. D'Alembert, en el Prólogo a la *Gran Enciclopedia*, sugería que los conocimientos humanos se deben a Memoria, Razón e Imaginación, representadas en diferentes disciplinas en formas distintas.

El investigador universitario tiene motivaciones diferentes del que trabaja para la industria: prestigio, fama, dinero, poder ("*publish*" or "*perish*"). El ascenso en la carrera académica depende del número e impacto de publicaciones originales evaluadas por pares (*peer review*). Se publica lo que la academia juzga valioso, a veces sin compromiso con necesidades societarias. Esta postura "internalista" y la idea de Thomas Kuhn sobre revoluciones y ciencia normal, asociada a paradigmas, invita a reflexionar sobre qué puede significar "ciencia comprometida", como pide la Academia de Medicina de Estados Unidos. Una integración de perspectivas al definir metas, objetivos, métodos e impacto de la investigación científica exige discernir entre invención, innovación y transformación.

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El ideario tecnocrático privilegia algunas formas de investigación. Las humanidades y las ciencias sociales tienen una valoración diferente (¿posiblemente menor?) de la asignada a las ciencias "duras"; los sistemas de financiamiento se modelan sobre la base de éstas y sus métodos.

Algunos sociólogos de la ciencia, como Robert Merton, incluyen el "desinterés" entre los caracteres de la investigación académica. Unido a los valores de honestidad, transparencia y reconocimiento de prioridades refleja un *ethos* científico que no siempre se ve en la realidad. Polémicas clásicas como *Montagner versus Gallo* o *Guillemin versus Schally* recuerdan que el mundo real no es el de las regulaciones aceptadas.

Las nociones de integridad y honestidad se relacionan con defensa de la autoría intelectual y las comunicaciones privilegiadas para revisores de proyectos y textos. Valores instrumentales como universalidad, escepticismo sistemático y desinterés (publicar en ciencia era al principio"*gift giving*") cobran importancia. En estudios multicéntricos o financiados por la industria a veces la escritura se delega a "redactores profesionales" que no participan en los estudios y solamente hacen publicables los resultados. La noción de "autor" se asocia a papeles específicos en el proceso.

Lo mismo vale para los procesos de difusión y publicación. La *Ingelfinger Rule* sigue válida: no comunicar al público hallazgos médicos no publicados en revistas supervisadas por pares. Las normas sobre integridad científica suelen ser diferentes para investigadores en la industria. Los investigadores académicos son "cronofílicos", se toman su tiempo, en tanto los industriales son "cronofóbicos": el tiempo es crucial en innovaciones que deben llegar al mercado o ser utilizables en plazos breves (no olvidar los estudios de salud pública que los gobiernos precisan para diseñar políticas adecuadas, que a veces no cumplen estándares de investigación académica)

La autorregulación de los científicos académicos se ha reemplazado por códigos profesionales y textos escritos accesibles a la comunidad; la confianza es esencial y muchos episodios del pasado la dañaron, especialmente en estudios con y en sujetos humanos. Los códigos y reglamentos suelen ser "*soft law*". La obediencia a leyes nacionales e internacionales prevalece.

Lo que se enjuicia y evalúa son acciones, no ideas abstractas o principios. La conciencia de los investigadores debiera prevalecer. Conocer regulaciones y textos difiere de enseñar ejemplos.

Suele abordarse la responsabilidad ética desde el punto de vista individual, listando transgresiones como plagio, falsificación o manipulación de datos, autorías reprochables (*ghost, guest, sold writing*) o inflación de citaciones mediante acuerdos. Debieran examinarse también los entornos institucionales; los "*rankings*" de universidades se basan en número e impacto de publicaciones e influyen en el prestigio y la sustentabilidad económica y/o política. Análisis conceptuales y bibliométricos recientes indican que autores hiperproductivos, caída en autorías primarias e inesperado aumento en múltiples afiliaciones institucionales, fenómenos a veces transitorios, inciden en conductas objetables. Interesante es que no dependen del comportamiento individual; pueden reflejar estrategias institucionales habitualmente no estudiadas y a veces fuera del alcance de los comités locales de ética de la investigación*(1,2)*. El análisis de tales prácticas es un urgente problema de investigación empírica y requerirá rediseñar textos normativos dirigidos a comportamientos individuales. Es conveniente reiterar que una *medición,* cuando se convierte en *objetivo*, deja de ser una buena medición. Evaluar competencias individuales e institucionales mediante indicadores cuantitativos requiere reformular el sustrato ético.

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FUNDAMENTACIÓN DE UN MÉTODO REALISTA PARA EL ANÁLISIS DE CASOS DE ÉTICA Y BIOÉTICA

José Carlos Abellán Salort[1]

Resumen: Mediante la revisión bibliográfica de publicaciones en lengua española y lengua inglesa de los últimos tres decenios, se realiza una crítica de los fundamentos y características de los métodos de análisis de casos en la bioética occidental contemporánea, y entre los más relevantes para el análisis de casos y problemas bioéticos resultan ser el Método Deliberativo (propio del principialismo, el consensualismo y el utilitarismo) y el Método Triangular (propuesto por el personalismo de base ontológica), los cuales presentan limitaciones de fundamentación y de aplicación práctica, respectivamente.

El autor justifica la necesidad de capacitar a profesionales y estudiantes para el análisis de casos prácticos en ética y bioética proponiendo un nuevo método, el “Método Realista”, que trata de reunir las virtualidades y utilidades del deliberativo y del triangular, superando sus deficiencias a partir de los planteamientos de la filosofía realista clásica y de la antropología de base personalista.

Palabras clave: bioética, metodología, realismo filosófico

Foundation of a realistic method for the analysis of Ethics and Bioethics cases

Abstract: Through a bibliographic review of publications in Spanish and English from the last three decades, a critique of the foundations and characteristics of case analysis methods in contemporary Western bioethics is carried out, among which the most relevant for the analysis of bioethical cases and problems turn out to be the Deliberative Method (typical of principlism, consensualism, and utilitarianism) and the Triangular Method (proposed by ontologically based personalism) which present limitations of foundation and practical application, respectively.

The author justifies the need to train professionals and students for the analysis of practical cases in Ethics and Bioethics, proposing a new method, the “Realistic Method”, which tries to bring together the virtualities and utilities of the deliberative and the triangular, overcoming the deficiencies of both from the approaches of classical realist philosophy and personalist-based anthropology.

Keywords: bioethics, methodology, philosophical realism

Fundamentação de um método realista para a análise de casos de ética e bioética

Resumo: Mediante revisão bibliográfica de publicações em língua espanhola e língua inglesa dos últimos três decênios, realizou-se uma crítica dos fundamentos e características dos métodos de análise de casos na bioética ocidental contemporânea, e dentre os mais relevantes para a análise de casos e problemas bioéticos resultaram ser o Método Deliberativo (próprio do principalismo, o consensualismo e o utilitarismo) e o Método Triangular (proposto pelo personalismo de base ontológica), os quais apresentam limitações de fundamentação e de aplicação prática, respectivamente.

O autor justifica a necessidade de capacitar profissionais e estudantes para a análise de casos práticos em ética e bioética propondo um novo método, o “Método Realista”, que trata de reunir as virtudes e utilidades do deliberativo e deo triangular, superando suas deficiências a partir das abordagens da filosofia realista clássica e da antropologia de base personalista.

Palavras chave: bioética, metodologia, realismo filosófico

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Introducción ¿Un nuevo método para el análisis de casos prácticos?

La bioética nació para tratar de ofrecer reflexiones y proyectar criterios éticos eventualmente útiles para quien trabaja en un laboratorio, en una farmacia o en un hospital; para quien tiene que redactar un programa político o una legislación sobre investigación biomédica, sobre salud sexual y reproductiva humanas o sobre cuestiones de salud pública; o para quien tiene que decidir si debería o no practicar un aborto, retirar un tratamiento médico o atender la solicitud de la muerte eutanásica en el final de la vida.

Ello obligaba a adoptar un enfoque multidisciplinar que integrase la perspectiva biológico-médica-biotecnológica; la filosófica-antropológica y la jurídico-social de la vida humana*(1)*.

Pero lo hace en un contexto histórico, filosófico y cultural caracterizado en Ética por un nihilismo práctico que ha negado la verdad, conformándose con la opinión y con el escepticismo práctico; un consecuente relativismo moral, que, separando cualquier imperativo moral de la realidad de las cosas, no admite que exista un bien objetivo ni conductas objetivamente inicuas y todo ello, aderezado por un nuevo hedonismo y un emotivismo moral que pretendería que lo bueno o lo justo queda establecido por lo que se siente, por lo que en cada momento y lugar es percibido como tal, individual y/o colectivamente.

No obstante, la herencia de la modernidad pervive en una combinación de un deontologismo que trata de sostener algunos principios éticos básicos de la tradición occidental como el valor de la libertad individual, la vida humana o la salud; y un preminente consecuencialismo ético, especialmente el utilitarismo, para el cual la prioridad de ciertos fines como la autonomía individual o el progreso científico justificarían cualquier medio.

En bioética, la corriente doctrinal dominante, que acoge estas bases filosóficas, es la "bioética de los principios", el llamado "principialismo". El principialismo de origen norteamericano es, por definición, procedimentalista, ya que basa toda bioética en el juego de la aplicación de los conocidos cuatro principios *prima facie* ("beneficencia", "no maleficencia", "autonomía" y "justicia") para resolver los conflictos bioéticos, renunciando a cualquier forma de normatividad y de fundamentación, que pudiera justificar la jerarquización entre ellos.

Deben advertirse, sin embargo, dos aspectos "de fondo": primero, que la exitosa "bioética de los principios" responde a una concepción pragmática de la bioética, aquella que habría asumido que el único fin que puede proponerse la bioética es el de tratar de orientar la resolución de los conflictos que pudieran plantearse en el ámbito científico y sanitario; y, segundo, que su formalismo no puede evitar que haya muy diversos modos de interpretar el significado de cada uno de esos principios, por ejemplo, que nos encontremos, en los debates bioéticos, con diversas interpretaciones de lo que significa, por ejemplo, "autonomía" o "beneficencia", que condicionan significativamente el sentido y alcance de su aplicabilidad.

Su carácter "formal", obviando intencionalmente la indagación sobre el contenido "material" y la teleología de la acción moral, favoreció su rápida difusión en un mundo postmetafísico y básicamente relativista y utilitarista, pero muy pronto evidenció sus limitaciones para ofrecer razones sólidas para recomendar una línea de actuación frente a otras, para ayudar en las situaciones concretas, recibiendo fuertes críticas*(2)* tan relevantes como para que sus primeros mentores buscaran "factores de corrección" para su teoría como fue la insuficiente propuesta de jerarquización formulada por Diego Gracia*(3)* o la incorporación del recurso a la "common morality" para solo limitar el riesgo inevitable del relativismo, en el caso de J. Childress*(4)*.

A pesar de esta carencia de una fundamentación metafísica y de una antropología filosófica que descubra la verdad sobre el ser humano y su dignidad personal universal, la bioética principialista es hoy por hoy la más extendida en el mundo y su enfoque formalista, procedimentalista, el que quiere enseñarse de modo generalizado, lo que ha sido criticado desde las filas de la única corriente bioética claramente alternativa, que es la *bioética personalista(5)*.

No existiendo una referencia objetiva para la moralidad, lo que ha venido imponiéndose en las cuestiones controvertidas bioéticamente (técnicas de reproducción humana asistida, aborto voluntario, investigación con embriones humanos, clonación con fines terapéuticos, eutanasia, vacunación obligatoria, etc.) son nuevas formulaciones del utilitarismo materialista que hace prevalente el valor de la autonomía individual y el progreso de la tecnociencia, y derivadas particularmente deshumanizadoras, como el neoeugenismo (neoeugenesia) *(6)* o, ya en el presente siglo, el posthumanismo y el transhumanismo, el cual se difunde como una ideología tecnocientífica de raíz materialista por reputados científicos y humanistas*(7)*.

Pero también han hecho fortuna las *éticas dialógicas,* en diversas versiones según la época y el lugar, como la *moral del consenso* o la *ética de mínimos,* corrientes de la ética que se recuperan de otras épocas históricas por adaptarse mucho mejor que cualquier otra al "mainstream" del pensamiento débil, erigido en el "pensamiento único". En este sentido, destacan las aportaciones de K. O. Apel, J. Habermas, incluso de H.T. Engelhardt a favor de las éticas dialógicas y el consensualismo moral. En España, la profesora Adela Cortina ha defendido la "ética de mínimos" como la posición más prudente en sociedades caracterizadas por un gran pluralismo moral*(8)*.

Desde el principialismo, se argumenta que, en sociedades pluralistas, las incertidumbres que presenta la bioética no pueden afrontarse con un enfoque "dilemático" (justo o injusto/ correcto o incorrecto), porque las situaciones no suelen ser de "blanco o negro", sino que hay una amplia gama de grises en ética y en un caso concreto, puede haber más de una línea de acción moralmente correcta. Según esto, errarían todas aquellas corrientes de la ética que confrontan las cuestiones éticas con un planteamiento decisionista, buscando resolver toda situación como un dilema, habitualmente desde la muy discutida *Teoría de la Elección Racional,* teoría que hizo fortuna en Economía, Ciencia Política y en Psicología, para tratar de explicar el comportamiento humano individual a la hora de tomar decisiones y criticada, entre otros por Amartya Sen, por la noción de racionalidad humana y su insuficiencia para dar razón de la dimensión social, relacional y moral de las motivaciones de las acciones humanas*(9)*.

Entonces, lo que procedería en ética y bioética, sería más bien un enfoque "problemático" que eluda la visión "dilemática" para abordar las situaciones y casos dudosos (la mayoría de las decisiones podrían presentar dudas al agente moral), porque siempre habría más de dos opciones éticas.

La desarticulación posmoderna de la ética, empezó cuando se pretendió privarla de cualquier fundamento objetivo, por ejemplo, con el argumento de la "falacia naturalista", la "naturalistic fallacy", tanto en la primera versión de la Ley de David Hume*(10)*, como en la de George E. Moore*(11)*, consiste en la crítica del *naturalismo* en ética, por la que sería ilegítimo pretender deducir prescripciones éticas ("deber ser"), con valor universal, a partir de hechos o proposiciones fácticas o de la naturaleza de las cosas ("ser").

Junto con ello, se diluyó la teleología intrínseca del acto moral. El racionalismo que cercena las facultades de la razón, instalado como *forma mentis* en Occidente, un pensamiento que limita la razón y fue censurado por J. Ratzinger*(12)*; la pérdida de prestigio generalizada de las éticas tradicionales, de base religiosa o civil, denostadas por ser tachadas de "maximalistas" e intolerantes; y la preminencia del voluntarismo y positivismo (moral y jurídico) han propiciado que los debates bioéticos hayan perdido rigor intelectual y salido de los espacios de la sociedad civil y se sustancien, con excesiva frecuencia, de modo irreflexivo, imperito e ideologizado, en sede política y jurídica (legislativa y jurisprudencial), imponiéndose posiciones morales ajenas muchas veces a la razón natural y a la razón de la verdad comprobada de los hechos científicos, al servicio de los intereses espurios de lobbies políticos y empresariales.

La sensación que deja al observador con algún criterio o formación moral y a todo aquel que se niega a sucumbir al desánimo escéptico y al ramplón "buenismo" imperantes, es la de que vivimos una crisis de valores éticos, donde se impone el individualismo y una falsa tolerancia, dogma del relativista que vive en sociedades pluralistas subyugado a la corrección política, según la cual, nadie podría definir lo que es bueno o malo, justo o injusto con pretensiones universalistas y cada uno puede hacer lo que desee, mientras no moleste a los demás, mientras se haga sin violencia, con el consentimiento del otro.

En cuanto a su funcionalidad para ayudar al mejor juicio moral, por ejemplo, ante decisiones del ámbito clínico-sanitario, se ha impuesto una bioética casuística, lo que resulta una lógica consecuencia del panorama arriba descrito: Si no hay criterios éticos ni bioéticos objetivos, seguros y universalizables, entonces se impone resignarse a que la bioética sirva para ofrecer "soluciones" o simplemente recomendaciones de actuación para los casos concretos, sin mayores ambiciones. Ayudar al investigador en su laboratorio o al sanitario en la clínica a tomar decisiones bioéticamente correctas, elucidar salidas para conflictos éticos concretos, sería la máxima aspiración de la bioética, desde la perspectiva de que será el consenso coyuntural, alcanzado en cada situación o supuesto concreto, el único juicio ético posible, que se basará en el prudente manejo del único método adecuado a este propósito, que, según sus defensores, es el de la *deliberación moral*, de base consensualista, donde la elección ética se sustancia tras una discusión entre posibles cursos de acción y unas "pruebas de consistencia" que aportarían una especie de validación objetiva ulterior considerando sobre todo la mayor positividad de las consecuencias de la línea de actuación mayoritariamente apoyada. Este sería el *método deliberativo* del profesor Diego Gracia, exportado por el prestigioso bioeticista a medio mundo, por sus virtualidades prácticas en un contexto bioético como el dominante en Occidente, relativista y utilitarista.

Metodología

La metodología de nuestro trabajo ha sido la revisión bibliográfica de artículos científicos y publicaciones doctrinales del presente siglo, en lengua española e inglesa, sobre los dos métodos más extendidos para el análisis de casos y problemas de Bioética, el *método deliberativo* y el *método triangular*, así como las más relevantes críticas sobre ambos, publicadas por comentaristas de los temas de bioética, bioética clínica y metabioética o bioética fundamental.

Nuestra valoración de ambas metodologías se basa en dicha revisión doctrinal, así como en la propia experiencia de análisis de casos en el contexto real de un CEAS (Comité Asistencial de Ética) de un hospital madrileño durante casi diez años, que nos llevó a diseñar un nuevo método que vengo poniendo en mi propia docencia universitaria de la Bioética en España.

Resultados: Constatamos las limitaciones de los métodos de análisis de la bioética

El método para el análisis de casos denominado "Método Deliberativo", que en España y en Hispanoamérica popularizó el profesor Diego Gracia, parte del principialismo, aunque su autor lo fue perfeccionando desde el convencimiento de que (…) *la deliberación como proceso no es solo el método de la bioética o de la ética sino de la racionalidad práctica en general, que es tanto como decir de la razón humana,* por lo que algún autor ha afirmado que sería el método idóneo para la bioética clínica e incluso para la discusión jurídica*(13)*. Para D. Gracia, (…) *La razón práctica es deliberativa. Pero la deliberación es una tarea difícil. Necesita de muchas condiciones: ausencia de restricciones externas, buena voluntad, capacidad de dar razones, respeto por los otros cuando están en desacuerdo, deseo de entendimiento, cooperación y colaboración. Éste es el marco para un proceso de deliberación verdadero. La deliberación descansa no en la "decisión" sino en el "compromiso". Dentro de este marco, casi todos los métodos existentes en bioética pueden ser útiles en alguna medida. Fuera de él, serán no sólo superfluos sino en ocasiones peligrosos(14).*

El método deliberativo tiene dos presupuestos filosófico-antropológicos apriorísticos que explican el alcance, las posibilidades reales que sus partidarios reconocen al procedimiento y justifican también la lógica de los pasos que proponen para el análisis de casos y situaciones donde pueda existir alguna duda moral.

En primer lugar, este método ha asumido, implícitamente, la inexistencia de actos moralmente "buenos" o "malos", en sí mismos, esto es, conductas intrínsecamente correctas e incorrectas. Rechazada cualquier moral "sustantiva" que pretenda decir cuál es el "bien", qué sea lo correcto, (porque lo justo, (lo bueno); y lo injusto (lo inicuo), no se pueden conocer, determinar ni reconocer), el juicio moral sobre un acto humano (una acción o conducta libre) nunca tendrá una pretensión de universalización, y sólo podrá elegir cuál sea, de entre las diversas opciones de actuación disponibles en ese caso ("cursos de acción") que parecen más o menos justos (buenos), aquél que sea el más correcto, por sus mejores consecuencias para todos los afectados por la decisión. No importa tanto alcanzar la "verdad moral" sino, más bien, el "consenso moral".

La determinación del curso de acción más correcto se logrará merced a la rigurosa aplicación de la "deliberación", un diálogo abierto, reglado, que sigue unos pasos*(15)*. Las conclusiones (y las consiguientes recomendaciones éticas de actuación) serían el resultado de un proceso democrático que definiría el nivel de la bondad ética de una acción por un consenso de personas competentes para ello, aplicando los principios de la bioética, descartando los cursos de acción que se consideren claramente rechazables por "extremos" y tratando de justificar dialógicamente entre las posibles, la línea "intermedia" que mejor respondería a unas pruebas de validación de carácter básicamente sociológico y jurídico (pruebas de legalidad, temporalidad y publicidad)*(16)*.

El segundo presupuesto, el antropológico, es coherente con el filosófico: El método deliberativo sería el único viable, posible para el ser humano, porque en su visión de este mismo ser humano, la razón se ha reducido a una razón "técnica". La razón humana, en su dimensión práctica, la que orienta los juicios morales hacia lo que ha conocido como lo bueno, se considera incapacitada realmente para conocer el bien. Del mismo modo que se cercenó las capacidades especulativas de la razón, para conocer la verdad, si lo "verdadero" no es asequible al entendimiento humano, tampoco lo es lo "bueno" (ni por extensión lo "bello"). Sin embargo, frente a las categorías postmodernas, creemos que existen conexiones entre el *bonum* y el *pulchrum* que merecen ser exploradas*(17)*.

En nuestra opinión, estos planteamientos han empobrecido la bioética con su pragmatismo ideológico, deudor de una cosmovisión equivocada, que mutila la razón humana, y exalta el diálogo y el consenso como la vía que nos alcanzará la única verdad y la única justicia posibles: la que definimos nosotros, los humanos, en cada momento y situación.

Siendo cuestionables sus dos presupuestos de partida, el método deliberativo también ha sido criticado por su limitada utilidad para ayudar en la valoración bioética de casos complejos. Algunas críticas al método deliberativo se encuentran en artículos de autores como Atienza *(18)*, De Lora y Gascón,*(19)* Requena Meana *(20)* o Seoane*(21)*.

Y aunque la deliberación es útil y buena como medio para conocer la verdad y el bien y porque ambos se *descubren*, (no se *crean* por el hombre) en un esfuerzo creativo comunitario, en diálogo con otros, el error es convertir el diálogo, la deliberación, en un fin. Incluso nos hacen dudar de su validez las diferentes modificaciones que se fueron introduciendo para evitar el riesgo de caer en una moral "situacionista" y para tratar de justificar algunos pasos del método, ante lo que Seoane propone una reformulación alternativa del método*(21:19-21)*.

El énfasis en el método, podría llevarnos a pensar que la utilidad marginal de la Bioética entonces se agota en la valoración bioética de casos clínicos y, aunque el método deliberativo parecía haberse impuesto sin discusión, sin apenas críticas, a pesar de sus graves limitaciones teóricas y prácticas, sin embargo, con el inicio del presente siglo, algunos bioeticistas se interesaron por la discusión metodológica, preguntándose qué método, qué procedimiento debía seguirse en la Bioética que se adjetivó de *bioética clínica* o incluso, *bioética de la actividad sanitaria(22)*.

Desde las filas del personalismo ontológico que difundió el profesor Elio Sgreccia, se propone como alternativa un método coherente con su concepción sustantiva y normativa de la bioética personalista, que es el denominado *método triangular*, cuya esencia y originalidad ha resumido acertadamente la profesora Marta Albert:

"El método triangular, concebido para ser aplicado a la docencia de la bioética, propone también tres fases fundamentales para la deliberación: el análisis de los datos, el examen de los valores y el momento de determinación de las exigencias morales del obrar para el caso concreto (qué debo hacer, o cuales son mis deberes en este caso). (…) ¿Qué introduce de nuevo el método triangular en la didáctica de la bioética? La respuesta es sencilla: una antropología. Los valores son entendidos como valores de la persona. El método triangular incorpora la antropología en el momento de la toma de decisiones, como un elemento integrador del proceso del razonamiento moral, lo que es coherente con su concepción de la bioética como ciencia al servicio de la persona".

Este método del personalismo con fundamentación ontológica pondrá en juego unos principios diferentes, los cuatro principios de la bioética personalista de "respeto de la vida física", "terapéutico o de totalidad", "libertad-responsabilidad" y "socialidad-subsidiariedad", coherentes con su visión integral de la persona*(23)*. Así, y no excluyendo la deliberación, que es indispensable para identificar el bien en cada conducta humana, pero comprendiéndola como un "medio" con el que cuenta la razón humana, no fundamentará su decisión/recomendación de actuación en el consenso mayoritario, sino en su coherencia con el bien de la persona, referente objetivo de moralidad.

El método triangular, con cuyo planteamiento antropológico y metodológico concordamos, adolece todavía hoy día de un desarrollo o concreción sobre sus fases y pasos concretos, pero podría servirnos de inspiración mejor que otros.

Este insuficiente desarrollo metodológico del personalismo ha encontrado en los últimos años, al menos en el plano epistemológico y antropológico, una "salida" a través del "Método de la experiencia integral"*(24)* propuesto por el filósofo español Juan Manuel Burgos, basado en su sugerente filosofía de un *Personalismo Integral(25)*.

El método de la experiencia integral supone una vía epistemológica novedosa, de aplicación para el conocimiento de las diversas áreas de la realidad, por lo que podría ser adecuada para sustentar una aproximación de carácter realista a los problemas bioéticos, que nos permita trascender las fronteras de un ontologismo radical, pero también las del deontologismo, el kantismo, el racionalismo cientificista o el consecuencialismo.

Discusión

La inadecuación del método deliberativo de los principialistas y consensualistas para la ética y la bioética, por su autolimitación apriorística filosófica y antropológica, y las dificultades del método triangular de los personalistas en el nivel de su aplicabilidad, su concreción práctica, nos llevaron a buscar una síntesis de las innegables virtualidades de ambos. Pero para hablar de la oportunidad de hallar un método alternativo para la bioética, entendemos que deberían admitirse tres presupuestos de partida:

En primer lugar, que toda metodología se orienta a un *fin*, puesto que el método es un medio, no es el fin, y que la discusión metodológica remite necesariamente a la de cuál sería la teleología de la ética y la bioética, desde el convencimiento de que el método es deudor, está condicionado por la finalidad que se quiera alcanzar o que se crea que se puede alcanzar. El método que se adopte debería ser el que mejor pueda servir a la finalidad, al objeto de esta ciencia, asumiendo que no siempre será el que se adapte mejor al pensamiento filosófico-moral dominante.

El problema que constatamos es que la bioética ha perdido de vista sus fines, aquellos objetivos que le daban sentido y virtualidad para contribuir al bien de cada persona y al bien común de la sociedad. Como consecuencia de ello, para muchos de sus estudiosos, la cuestión del método tendría una relevancia desproporcionada, sería lo único importante. Si la bioética no se puede orientar hacia los fines (desvelar lo bueno, lo justo, etc.), entonces lo metodológico se convierte en el fin, lo cual es ideológico. Y hay que advertir que, en tanto que ideológica, tal desvirtuación de la bioética debería ser rechazada, porque nos limita al espacio de lo que una racionalidad meramente técnica y procedimentalista puede ofrecer. Significa aceptar que no hay más remedio que pensar en el "cómo" renunciando al "qué" y al "para qué".

En segundo lugar, que, existiendo concepciones éticas y bioéticas distintas y claramente diferenciables, no tiene por qué aceptarse que exista un único método posible para la ética y la Bioética. Igual que hay diversas corrientes de pensamiento, enfoques y sensibilidades en ética y en bioética, podrían existir varias metodologías de análisis válidas, y deberían al menos considerarse en un debate racional, abierto y respetuoso, en sociedades pluralistas como las de nuestro entorno.

En este aspecto, lo contrario sería sucumbir ante una pretensión ideológica claramente totalitaria, como la que, de forma lamentablemente inadvertida para la mayoría de las personas, sufrimos hoy con la intolerante imposición del pensamiento único, nihilista y relativista antes descrito.

En tercer lugar, que el criterio de validación para preferir un método frente a otro no debe ser su mejor adaptación a los consensos mayoritarios, filosóficos y especialmente los morales, de una época y lugar, ni tampoco su mayor utilidad o idoneidad funcional para llegar a recomendaciones de actuación más fácilmente aceptables por la sociedad. Este pragmatismo funcionalista, propio de metodologías principialistas o procedimentalistas, sólo garantiza agilizar el debate de algunas cuestiones o, simplemente, contentar a la "corrección política". Nos cierra a un "casuísmo" que, descartado cualquier deduccionismo desde principios universalizables, también impide proceder inductivamente a identificar criterios generales desde los supuestos concretos, ya que tampoco admitiría que la valoración ética de un caso pudiera universalizarse en grado alguno para casos idénticos o análogos.

Por todo lo anterior, aun admitiendo que es procedente reflexionar sobre el método para la ética y la bioética, en este trabajo partimos de nuestro rechazo a la ideologización del método, al tiempo que nos proponemos argumentar la conveniencia de seguir un procedimiento de análisis de casos, casos prácticos en ética y bioética, que ayude a su mejor ponderación en cuanto que ese método, superando las limitaciones antedichas en el uso de la razón práctica, no abdique a priori de los fines de estas disciplinas sino que, al contrario, los tenga presentes en todo el procedimiento.

Nuestro enfoque: La filosofía realista y la razón práctica ante los casos de análisis

El método de análisis ético y bioético de casos que proponemos es radicalmente distinto del procedimentalismo que caracteriza el método deliberativo porque nuestra alternativa se fundamenta en una filosofía moral en la que su raíz es una metafísica y una antropología filosófica concreta, la del realismo clásico, cuyas claves fundamentales se pueden encontrar magistralmente formuladas en la obra del filósofo español contemporáneo, Antonio Millán-Puelles*(26)*. Las claves diferenciales son, pues, filosóficas, porque partiremos de la confianza en la potencialidad real de la razón humana para conocer la verdad, el bien y la belleza, sobre el presupuesto de que la realidad está ahí, trasciende al ser humano y se ofrece a su conocimiento.

El realismo que proponemos en la base de nuestra propuesta metodológica recupera una antropología filosófica perenne que concibe al ser humano como un sujeto personal y aquella concepción epistemológica premoderna, en la que el ser humano, a pesar de las limitaciones cognoscitivas inherentes a su condición finita y contingente, es capaz de conocer, a través de sus sentidos y de su entendimiento racional, la realidad que le circunda y es capaz de conocerse a sí mismo.

La persona, distinta esencialmente de los otros entes, incomunicable desde el punto de vista de su radical unicidad y especificidad ontológica, es capaz de un encuentro creativo con ellos, como sujeto cognoscente que se trasciende a si mismo y así conocer la esencia de si misma y de los otros entes reales, materiales o inmateriales.

Frente al inmanentismo e idealismo gnoseológicos y a las también variadas concepciones antropológicas racionalistas, dualistas y materialistas que en sus diversas versiones impulsó la Modernidad, nuestra visión adopta una metafísica y antropología realistas en la que la persona no "construye" desde las ideas o desde el lenguaje; sino que "descubre" con una razón abierta, la verdad de las cosas y de si misma. Los juicios y las consiguientes certezas que alcanzamos en nuestro conocimiento se basan pues en la realidad, en lo que muestran las "cosas" (res/i), las cuales poseen una esencia, podríamos decir una naturaleza asequible a nuestro intelecto racional.

Simplificando mucho, queremos decir, frente a las tesis empiristas, racionalistas, escépticas y relativistas, que el entendimiento humano, eligiendo las vías y adaptando el método a las distintas dimensiones de la realidad, puede conocerla, siempre limitadamente, pero verdaderamente, en el sentido de que es posible que nuestro juicio, lo que decimos del objeto de nuestro conocimiento se adecúe a lo que "es" (*verdad lógica*). Y que lo que las cosas y las personas *son*, no depende de que las conozcamos, de cómo las conozcamos o de lo que digamos de ellas, sino que son lo que son, independientemente de que sean o no conocidas (*verdad ontológica*).

Como consecuencia de esta capacidad del *entendimiento* humano, nuestra otra facultad que es la *voluntad* estaría habilitada para desarrollar actos, conductas, caracterizadas por su libertad, que llamamos *actos humanos*. En ellos, el intrínseco dinamismo finalista de la acción humana, puede dirigirse a alcanzar lo bueno, lo justo, porque el entendimiento, conocida la verdad de la persona y de las cosas, procurará siempre lo que contempla como un bien. Bien de la persona y bien de las cosas que no depende de lo que nosotros opinemos, sino de lo que vemos, descubrimos, en una contemplación respetuosa de ellas, libre de apriorismos y constructivismos de cualquier signo, abiertos a lo que ella tenga que decirnos.

La razón práctica que se mueve en este planteamiento realista descubre en la persona y en la realidad un orden que se ajusta a una regulación ínsita, inmanente a ellas, una ordenación objetiva e inmutable de la realidad, que junto a elementos materiales integra también elementos morales y ese orden inscrito en la realidad, lo descubrimos como vinculante para la libertad humana.

Esto significa que hay un modo ordenado, correcto (ético) de relacionarnos con nosotros mismos, con el resto de las personas y con las cosas, conforme con sus respectivas naturalezas, que representan un imperativo moral ineludible para el sujeto moral que es la persona, y que se expresa en normas éticas que descubrimos en su objetividad ("ley natural" o normas morales objetivas) y nosotros vendremos obligados a cumplir, ajustando su aplicación de acuerdo a nuestra conciencia (norma próxima subjetiva de la moralidad) en cada caso y situación singular.

Conclusión propositiva

Desde el punto de vista del método para la bioética, lo que proponemos es un procedimiento que caracterizamos de "realista", porque:

En cuanto a su punto de partida, la filosofía que lo inspira es realista, como en el método de los personalistas, en el sentido de que se fundamenta en la tesis de que la razón humana puede conocer el bien que conviene a la persona, a su naturaleza y dignidad.

La dinámica del análisis tendrá siempre como referencia la persona, lo que comprende los *bienes morales* que comporta su dignidad, (vida física, libertad, salud, etc.) los cuales deben ser siempre protegidos. En este sentido, si en una situación clínico-sanitaria o de investigación biomédica, o incluso en la preparación de una norma biojurídica, se apreciara un posible conflicto entre estos bienes de la persona, la deliberación sobre cuál, en cada caso, deba tener prioridad no se resolverá en la aplicación arbitraria de principios *prima facie* (como en la metodología principialista); ni se basará simplemente en la opinión mayoritaria sobre la importancia coyuntural de unos valores frente a otros (como en las éticas dialógicas); o sólo en las consecuencias previsibles de una jerarquización u otra.

En cuanto al fin, al propósito al que aspira y se orienta, también es realista. Contra el pragmatismo de las metodologías consensualistas, deliberativas y casuísticas, la razón práctica que orienta el juicio moral no tiene por qué conformarse con aceptar elegir entre opciones de actuación que se seguirían en aplicación de un principio frente o contra otro porque, en realidad, los que aplican el método deliberativo no creen que puedan encontrar la acción justa, buena, sino solo la que no siendo "extrema" (¿?), pueda ser aprobada mayoritariamente si supera unas pruebas de consistencia cuyos parámetros siempre serán variables y discutibles.

Nuestro juicio bioético, que se perfecciona tras un diálogo de quienes creen en la verdad y el bien de la persona pero saben que la búsqueda de ambas debe ser comunitario, sumando perspectivas, y no "negociando" entre opiniones sobre los principios y valores percibidos, deberá sin embargo incorporar la consideración de las consecuencias de la acción recomendada, como todo acto humano, pero entendiendo que la acción moral correcta éticamente tiene en su origen la característica de su libertad, y en su teleología que es la consecución del bien integral de la persona.

Como alternativa integrativa a los métodos *Deliberativo* y *Triangular,* venimos aplicando en nuestra enseñanza de Ética y Bioética el que denomino “Método Realista”, para el análisis de casos y problemas de índole ética y bioética, que requiere una mínima formación teórica previa antropológica y moral.

Recomendamos anticipar una *formación básica* en la filosofía realista y en la antropología personalista, para que ambas se mantengan como los “ejes” del diálogo racional que sustanciará la valoración bioética de cada caso, una formación previa a iniciarse en el análisis de casos y problemas, con los siguientes delineamientos:

- El conocimiento del Ser Humano. Realismo (trascendencia) vs. idealismo (inmanencia) del conocimiento humano. El problema de la verdad.
- Concepto de persona. Persona y personalidad. La dignidad y la libertad de la persona.
- Ética y Moral. Teoría de la acción moral: Dinamismo finalista, el bien y sus tipos. Factores de la moralidad. Objetividad y subjetividad en la moralidad. Responsabilidad, mérito y virtud. Ética y felicidad. El valor moral. Principios de la ética más importantes. El proyecto personal como proyecto ético. Principales corrientes de la Ética.

La formación teórica previa del estudiante de Bioética debería deseablemente completarse con unas bases de *Bioética General*, que debería incluir, al menos, referencias a los siguientes aspectos:

- Concepto, características, historia y fuentes de la Bioética.
- Principales corrientes doctrinales en la bioética actual.
- El problema metodológico en la bioética. Exposición teórico-crítica sobre los métodos de análisis bioético de casos más importantes.
- Introducción al bioderecho.

El MÉTODO se resume en las siguientes fases:

El punto de partida del *Método Realista*: La selección y enumeración de los actos y conductas humanas éticamente relevantes y la identificación de los bienes morales en juego.

Fase de Análisis:

- Evaluación de las *Condiciones de libertad* de los diversos agentes morales, en cada decisión u opción moral.
- Comentario sobre los *Factores de la Moralidad* en cada conducta (*Finis operis*, *finis operantis* y *circunstancias*).
- Primera valoración preliminar sobre la licitud/ilicitud moral de la/s decisión/es comentadas.
- Ponderación de la responsabilidad moral en los actos ilícitos de los actores aplicando los Principios Generales de la Ética (*Mal Menor; Totalidad o Terapéutico; Doble Efecto o Efecto Secundario Indirecto*).
- Evaluación ética de las conductas seleccionadas desde la perspectiva de las diversas teorías o corrientes de la ética/bioética (*Utilitarismo, Principialismo, Deontologismo, Personalismo, etc.*). Esta valoración comparativa es procedente en la enseñanza de la Bioética, no tendría lugar en el análisis de un caso en un Comité.
- Fase Conclusiva: Valoración ética final del comité o grupo de análisis, con las recomendaciones que procedan.

En el caso de usar el método en la docencia: Valoración personal: ¿Qué puede enseñarnos este caso práctico? ¿Cómo habría actuado o debería actuar yo en situaciones como las presentadas en el caso? Igual que en el epígrafe 2.5., el docente puede opcionalmente proponer este espacio para la opinión del estudiante.

Recordemos que el método de fundamentación realista que proponemos no pretende ser solo un procedimiento más, alternativo al método deliberativo o a las soluciones procedimentalistas de los principialistas y casuistas, para el análisis de casos en los ámbitos clínico-sanitario, biotecnológico y de la investigación biomédica.

Entendemos que es más que un método, más que un procedimiento para resolver conflictos porque, como hemos explicado antes, supone una forma de confrontar, estudiar las situaciones con una antropología y una filosofía sobre el conocimiento humano y la ética en su fundamento, que determina una concreta interpretación de la acción moral, en la que es esencial una natural teleología hacia la prosecución del bien integral de la persona humana.

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NARRATIVE MEDICINE IN CHINA: A CRITICAL REFLECTION

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Abstract: In recent years, narrative medicine has become a hot topic in Chinese humanistic medicine and has gained considerable influence. It is believed that narrative medicine can provide a constructive approach to balancing bio-medicine and humanities sciences, but there are many anti-narrative factors in China's culture and medical practice. It is controversial whether narrative medicine can improve medical diagnosis and the doctor-patient relationship in China. Therefore, despite many researchers believing that narrative medicine is very suitable for China, some critical reflections are still needed, so as to avoid doctors and patients spending too much energy on narrative, which may lead to treatment opportunities missing or create new troubles.

Keywords: bioethics, narrative, patient, cultural difference

Medicina narrativa en China: una reflexión crítica

Resumen: En los últimos años, la medicina narrativa se ha convertido en un tema candente en la medicina humanística china y ha adquirido una influencia considerable. Se cree que puede proporcionar un enfoque constructivo para equilibrar las ciencias biomédicas y las humanísticas, pero existen muchos factores antinarrativos en la cultura y la práctica médica de China. Es controversial esta puede mejorar el diagnóstico médico y la relación médico-paciente en China, por lo tanto, a pesar de que muchos investigadores creen que es muy adecuada para esta nación, todavía son necesarias algunas reflexiones críticas para evitar que médicos y pacientes gasten demasiada energía en la narrativa, lo que puede llevar a perder oportunidades de tratamiento o crear nuevos problemas.

Palabras clave: bioética, narrativa, paciente, diferencia cultural

Medicina narrativa na China: uma reflexão crítica

Resumo: Em anos recentes, a medicina narrativa tornou-se um **tópico** quente na medicina humanística chinesa e ganhou influência considerável. Acredita-se que a medicina narrativa possa fornecer uma abordagem construtiva para equilibrar ciências biomédicas e humanidades mas há muitos fatores anti-narrativa na cultura prática **médica** chinesa. É controverso se a medicina narrativa pode melhorar o diagnóstico médico e a relação **médico-paciente** na China. Portanto, apesar de muitos pesquisadores acreditarem que a medicina narrativa é muito adequada para China, algumas reflexões críticas ainda são necessárias para evitar que médicos e pacientes gastem muita energia em narrativas que possam levar a perder oportunidades de tratamento ou criar novos problemas.

Palavras chave: bioética, narrativa, paciente, diferença cultural

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1. Introduction

2018 was a milestone year for the development of narrative medicine in China. A specialized journal named *Narrative Medicine* was officially launched with the support of China's National Health Commission, and narrative medicine became a part of CNHC's standardized training program for resident physicians. In the same year, Charon, the main advocate of narrative medicine, attended the International Conference on Medical Humanities held in China and delivered a keynote report. Since then, narrative medicine has been rapidly and widely introduced into Chinese clinical practice and research, medical student education, hospital management, and other fields. An explosive research trend of narrative medicine prevailed in China: over a hundred studies on narrative medicine were published in journals every year, and numerous hospitals carried out practices on narrative medicine*(1,2)*.

Why does the Chinese medical community pay such great attention to narrative medicine? The possible reasons are as follows: (i)narrative medicine is believed to supplement doctors' diagnosis with information that cannot be provided by technical medicine*(3,4)*, (ii)narrative medicine is considered to be able to improve the deteriorating doctor-patient relationship*(5,6)*, (iii)narrative medicine is believed quite in line with Chinese medical culture and can enhance the connection between care and cure*(7-9)*. Despite many opinions advocated by narrative medicine do provide useful references for medical practice, considering the anti-narrative factors in Chinese culture and medical conditions, we have reasons to believe that some reflection is needed on the effectiveness and potential risks of narrative medicine.

2. Does narrative medicine help doctors make better diagnoses?

Charon criticized modern medicine as an empty medicine and believed that narrative knowledge can help doctors make better diagnoses*(10:6)*. Charon shares the phenomenological views of Carel and Toombs, and rejects the *Cartesian paradigm* which is seen as treating illness as a physical problem*(11:93-94)*, as Toombs puts it, illness results not only in a disintegration of body but in a disintegration of self and world*(12)*. Charon believes that scientific knowledge is powerless in seeking meaning for patients. Narrative knowledge is introduced as a remedy in medicine, which aims to providing narrative tools that enable doctors to understand the plight of patients, because narrative knowledge is what one uses to understand the meaning and significance of stories through cognitive, symbolic, and affective means, so narrative medicine is not only a caring concept that respects patients, but also has cognitive value like bio-medical knowledge, through which we can get the real information of patients *(13)*, what distinguishes narrative knowledge from scientific knowledge is its ability to capture the singular, irreplicable, or incommensurable things*(10:45)*, narrative have the power to improve healthcare by increasing the accuracy and scope of clinicians' knowledge of their patients and deepening the therapeutic partnerships they are able to form*(11:1)*. In a word, scientific knowledge is adept at diagnosing the bodies of patients, while narrative knowledge can understand the meaning of their lives. We can improve this native ability to enter others' narrative worlds by practice and to visualize others' perspectives on these worlds*(14)*, and narrative writing in clinical settings makes information audible and visible that otherwise would be ignored *(15)* . In other words, doctors with narrative skills can connect many fragmented elements into an understandable story about patients, and make it as narrative knowledge that provides a basis for them to make diagnoses.

Without considering whether Charon's criticism of the *Cartesian paradigm* of modern medicine is a straw man fallacy, we agree with her critical viewpoint on scientific knowledge and the role that narrative knowledge plays in medicine and human life. However, narrative knowledge also requires the epistemological examination as same as scientific knowledge. Most critics of narrative medicine do not accuse it of having no value, but often question narrative medicine exaggerates its cognitive benefits *(16-18)*. Similarly, the cognitive effects of narrative medicine in Chinese clinical activities are not as good as imagined. Charon believes that, with narrative knowledge, we enter others' narrative worlds and accept them—at least provisionally—as true*(10:9-10)*.Whether doctors can enter the patient's real world through narrative skills largely depends on the patient's narrative desire, but in most cases, personal life is not the content of communication between strangers in China, thus the narration between doctors and patients can not guarantee to get an accurate description of the real situation of the illness or the real experience of the patients. From the perspective of traditional Chinese medical culture, the diagnostic procedure follows the four steps of “inspection, auscultation and olfaction, inquiry, and palpation”, in which the inquiry is related to the narrative. Although scholars have pointed out that inquiry reflects the compatibility between traditional Chinese medical culture and narrative medicine*(7, 9)*, they have neglected that the doctor’s inquiry is only limited to the patient’s symptoms, past and family medical history, related living habits and environment, and not involving other life events of the patient, especially when they face female patients. And even though Chinese doctors ask patients about their daily lives, patients do not always tell the truth, especially when they intentionally conceal it for dignity and privacy. The assumption that patients have a universal desire to narrate is not in accordance with Chinese culture, because many people do not have the desire to reveal their life experiences to strangers. When doctors try to condense what the patient is telling into a meaningful story through narrative, the patient’s life may not actually be like this*(19)*. It may be meaningful to introduce narrative knowledge to Chinese doctors as a method of improving doctor-patient communication, but it might disappoint doctors as a diagnostic tool. It is difficult for doctors to obtain useful information through narration, and in some cases, they may even be disturbed by the confused results.

3. Can narrative medicine improve the doctor-patient relationship?

According to Charon, narrative medicine defined as medicine practiced with the narrative competence to recognize, absorb, interpret, and be moved by the stories of illness, it will more ably convey knowledge and regard*(10:vii)*. Scholars have responded positively to Charon and believe that narrative medicine can improve the doctor-patient relationship in China. But as a powerful force that can produce different effects, narrative must be taken into account for its potential risks.

First, narrative medicine may enhance the inequality of doctor-patient relationship, because the narrative may extend the social role of the doctors, and give extra responsibility beyond their current professional scope, which may lead to the potential risk of expanding medical paternalism. At this point, narrative medicine is spiritually arrogant and potentially harmful*(20)*. Compared with patients, doctors have similar advantages in narrative knowledge as in scientific knowledge. They dominate the narrative process, and the patient’s experience still follows the doctor’s narrative rules. Patients in medical narratives still lack autonomy, the passive position of patients has not been changed, they are even more likely to be in a situation similar to what Foucault calls ‘medical gaze’*(21)*. The involvement of narrative in medicine may even increase the risk that a doctor with ulterior motives controls patients’ lives. Narrative medicine, as a tool, has uncertainty in practice, just like technical medicine. The power of discourse is never one-sided, and narrative carries unpredictable dangers.

Second, narrative may promote understanding and respect between doctors and patients, and may also worsen doctor-patient relationships. Although narration may be helpful to some people, it may also harm others. Overemphasizing the application of narrative in medical activities may bring unnecessary troubles to doctors and unrealistic expectations to patients*(20)*, and it is sometimes a dangerous practice for doctors to express empathy to patients through narration*(22)*. If we only consider the benefits of narration while ignoring its drawbacks, it may lead to some negative consequences. Too many incidents have shown that patients’ excessive expectations will causes greater pain or anger when their expectations are not realized, and this is often an important risk factor that causes doctor-patient conflicts and violent injuries to medical staff in China*(23-25)*. Narrative also has uncertainty in ethics, because the narrator’s subjective experience and authority actually set questions for ethical reflection and determine the direction of solutions*(26:264)*. Although Charon points out that narrative in medicine is co-built by doctors and patients, based on empathy rather than judgment, correction, or education*(11,41)*, medical narrative is not aimless and still needs to follow the rules of discourse. The leaders of medical narratives are often doctors with narrative skills rather than patients.

If there is no equal communication between doctors and patients, whether doctors regard the patient’s body as a pile of data or treat the patient’s life as a literary text, it may bring the same cold ending to the doctor-patient relationship. In this case, there is not much difference between a patient being examined or being read, just like it is hard to say who is in a better situation between a patient being examined in a hospital and a suspect being questioned at a police station. Some Chinese patients may not feel respected by doctors just because their illness has become a story waiting to be read, and they may even feel more distressed because both their body and life have become an object to be observed, which can lead to embarrassment, resentment and hostility toward the doctor.

4. Cultural differences and anti-narrative factors in China

Considering that narrative is a cultural activity, cultural differences are undoubtedly an indispensable factor in constructing medical narratives. Narrative medicine emphasizes diversity, but it also has a universalist tendency to overlook cultural differences. Although Charon noted the cultural differences in narrative*(10:28;11:43)*, and dedicated to the cross-cultural application of narrative medicine*(11,14)*, she actually used a specific narrative mode to tell stories that happened in different cultures.

First, Charon only reflects a unique narrative value of the West. She often emphasizes that narrative medicine embodies a universal value*(10:78)*, as she quoted Jens Brockmeier as saying, neither our understanding of who we are nor our very existence in a cultural world can be separated from the stories that we and others tell about ourselves*(11:110)*. However, it is not shared by everyone. Schiff, for example, states that, in describing our project as narrative, we are reifying a Western, arguably middle and upper class, concept as the universal mode of shaping and articulating subjective experience... Our mistake is to think that everyone must be like*(27)*. Story metaphors attempt to explore a structure of meaning shared by all humans, but as Strawson's widely cited argument points out, the aspiration to explicit narrative self-articulation is natural for some—for some, perhaps, it may even be helpful—but in others it is highly unnatural and ruinous*(28)*. The same goes for narrative in medicine. It is a limited practice, and not every illness becomes a story, nor does everyone or every culture assume illness as a meaningful story. When narrative medicine is applied as a universal method to grasp patients' life experiences, it is likely to construct a meta-narrative described by Strawson. If we ignore the cultural differences in China and copy the theories and practices of Charon, it may even be harmful*(19)*. The universal proposition of narrative medicine needs to be limited, we should avoid isolating and distressing people by limiting ourselves to specific forms of narrative, and to narrativity per se*(16)*, and avoid the too far reaching ambitions on behalf of narrativity in relation to clinical medicine*(29)*.

Second, whether the purpose of narrative medicine can be successfully achieved largely depends on whether the medical resources are sufficient or not, because the narrative requires doctors and patients to invest enough time. Charon's narrative ideals are based on the cultural and medical conditions of developed Western countries, while China is not entirely the same. When Charon expressed expectations for the future of narrative medicine, she described Hannah Arendt's ideal of the polis: the village square at which gather free people, each becoming who he is and who she is by virtue of the events enacted among them all. Collectively, we declare our freedom*(30)*. It presents us with an ideal medical environment where doctors and patients participating in narratives can have the opportunity to explore themselves leisurely as in daily life. Meanwhile, it means that the foundation for in-depth dialogue between doctors and patients is that they both have sufficient free time. But in China, many reasonable anti-narrative factors are inevitable, especially considering the time factor.

The core of narrative medicine is to cultivate the narrative skills of doctors. While for Chinese doctors, they do not truly have free time to share with patients because they need to face more patients than their Western counterparts, and the time they can share with each patient is very limited*(31)*, and there is often more than one patient in the consulting room. In addition, Chinese doctors need to squeeze time to update their skills and knowledge constantly. It is impossible to expect them to spend a lot of time training narrative skills. In fact, most doctors have a potential resistance to narrative, sharing the pain of patients in depth can also increase the professional pressure on them*(32)*. They are accustomed to making medical records difficult to recognize and keeping a distance from patients, in order to avoid the time occupation and potential conflicts caused by narrative*(19)*. For many Chinese patients, they are also unwilling or even more unwilling than doctors to waste time on narrative, because the time they can get from doctors is usually only a few minutes. They also care about whether doctors have a good attitude, but they don't want to spend their precious treatment time telling stories. Therefore, in the short period of diagnosis, they value a doctor's scientific knowledge more than narrative knowledge. They prefer doctors to solve their physical problems rather than gain doctors' understanding of the meaning of their lives. As mentioned earlier, many Chinese patients may even refuse to speak in such a cold environment like a hospital. The nature of medical narratives may sometimes threaten dignity, and patients may need to directly confront or resist the narratives to reclaim dignity*(33)*. Some Chinese patients even refuse to start a story about themselves with strangers. They tend to feel uncomfortable about narrating with doctors, and do not want to bring their lives into the hospital and share with doctors, nor do they want their experiences in the hospital to continue in their lives. Chinese doctors and patients often find it difficult to form a narrative helpful for treatment within a few minutes, their resistance to narrative reflects the rightly concerns about time cost and personal privacy. In that case, narrative medicine is difficult to accomplish the desired results, it mostly serves as a placebo.

5. Conclusion

It should be pointed out that we are not opposed to the application of narrative medicine. On the contrary, as many scholars have pointed out, narrative medicine can play a role in the current medical reform in China*(34, 35)*, and provide a good start for the current exploration of medical humanities*(8)*. However, the application of narrative medicine in China still lacks critical reflection and localized development. Although many supporters have described numerous cases that benefit from narratives, there is little research discussing the adverse consequences of narrative medicine. Therefore, this might be a result of survivor bias or publication bias, as it is well known that studies that demonstrate effectiveness and safety are more likely to be published and reported.

Narrative medicine and technical medicine both imitate and reproduce what happens to people in diseases. The former imitates and reproduces patients' experiences through stories, while the latter presents physical states through data. Narrative medicine does not oppose technological medicine, but advocates that if we can achieve this dual imitation, we will obtain more information. Just as technology may not always bring benefits to humanity, the narrative may not always promote understanding and respect between people. Narrative may enable doctors to better treat and understand patients, or it may put patients in worse situations, such as leading to medical hatred or medicalizing patients' lives.

With the increasing role of narrative in medicine, people not only need to focus on the positive value of narrative medicine, but also need to maintain a critical spirit towards the limitations and risks of narrative. Narrative medicine is a dynamic and hopeful attempt, but as a tool, it should face similar questions as technical medicine. It is necessary to consider cultural factors when applying narrative medicine. This is not to deny its value, but to make this tool work better for us. Morris, for example, states that, narrative medicine is no panacea, within medicine, narrative is an instrument suited to particular tasks, it must be matched to the tasks it performs well, so that we do not blame a stethoscope for its failure to turn a screw*(36)*. Narrative medicine is not a universal tool, it may fail due to cultural differences. If the narrative is practiced without considering the object and environment, as if it is a treasure box for solving all medical problems, it is very likely to become a garbage dump that conceals the real problems. The application of narrative in medicine can be either a technology of exploring oneself as described by Charon, or a technology of power similar to Foucault, which may contribute to the long-standing paternalism in medicine. Narrative medicine requires both epistemological and ethical considerations, as well as considerations of medical conditions and time efficiency. If too much energy is focused on narrative, it is possible for doctors and patients to miss the real opportunity to solve the problem, and may also incur new risks.

Narrative medicine has become a global effort, and its application and development in China is not to add some elements of Chinese culture that match its temperament, but to establish a narrative framework that conforms to Chinese culture through questioning and self reflection. Otherwise, when we view the life experiences of patients as text, it will not be warmer than regard their bodies as data.

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THE ETHICAL RISKS AND SOLUTIONS OF THE ALGORITHM BLACK BOX IN MEDICAL ARTIFICIAL INTELLIGENCE

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Abstract: The application of artificial intelligence (AI) in the medical industry is becoming increasingly widespread. Relying on its powerful machine-learning capabilities, it has gradually become an important auxiliary diagnostic device. At the same time, it gradually has a certain degree of autonomy. But this also leads to the problem of lack of transparency in algorithms. A critical ethical issue known as the "algorithmic black-box" problem has emerged. For the ethical challenges associated with the opacity of medical artificial intelligence algorithms, enabling artificial intelligence systems to have reasoning and moral judgment abilities, namely constructing medical artificial moral agents, has been proposed as a viable solution. This article analyzes the solutions of constructing medical artificial moral agents including "top-down" and "bottom-up" approaches. After that, the new hybrid ethical design approach is proposed, integrating the advantages of both top-down and bottom-up approaches.

Keywords: medical artificial intelligence, algorithmic black-box, top-down approach, bottom-up approach, hybrid approach

Los riesgos éticos y las soluciones de la caja negra algorítmica en la inteligencia artificial médica

Resumen: La aplicación de la inteligencia artificial (IA) en la industria médica se está extendiendo cada vez más. Basándose en sus potentes capacidades de aprendizaje automático, se ha convertido gradualmente en un importante dispositivo auxiliar de diagnóstico y, al mismo tiempo, de forma gradual, con cierto grado de autonomía. Pero esto también conduce al problema de la falta de transparencia en los algoritmos y, debido a esta situación, ha surgido un cuestionamiento ético crítico, conocido como el problema de la "caja negra algorítmica". Para los desafíos éticos asociados con la opacidad de los algoritmos de inteligencia artificial médica se ha propuesto como solución viable permitir que los sistemas de inteligencia artificial tengan capacidades de razonamiento y juicio moral, es decir, construir agentes morales artificiales médicos. Este artículo analiza las soluciones para construirlos, incluidos los enfoques "de arriba hacia abajo" y "de abajo hacia arriba". Después de eso se propone el nuevo enfoque de diseño ético híbrido, que integra las ventajas de ambos enfoques.

Palabras clave: inteligencia artificial médica, caja negra algorítmica, enfoque de arriba hacia abajo, enfoque de abajo hacia arriba, enfoque híbrido

Os riscos e soluções éticas da caixa preta algorítmica em inteligência artificial médica

Resumo: A aplicação de inteligência artificial (IA) na indústria médica está se tornando amplamente difundida. Contando com poderosos recursos de aprendizado de máquina, ela gradualmente ase tornou um importante dispositivo auxiliar de diagnóstico. Ao mesmo tempo, ela gradualmente tem um certo grau de autonomia. Mas isso também leva ao problema de uma falta de transparência em algoritmos. Um aspecto ético crítico conhecido como o problema da "caixa preta algorítmica" emergiu. Para os desafios éticos associados com a opacidade dos algoritmos de inteligência artificial médica, permitir que os sistemas de inteligência artificial tenham capacidade de raciocínio e julgamento moral, nomeadamente a construção de agentes morais artificiais médicos, foi proposto como uma solução viável. Esse artigo analisa as soluções de construção de agentes morais artificiais médicos, incluindo abordagens "de cima para baixo" e "de baixo para cima". Depois disso, a nova abordagem de planejamento ético híbrido é proposta, integrando as vantagens de ambas abordagens de cima para baixo e de baixo para cima.

Palavras chave: inteligência artificial médica, caixa preta algorítmica, abordagem de cima para baixo, abordagem de baixo para cima, abordagem híbrida

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Introduction

The rapid development of technological progress has had a profound impact on society in many aspects, including health area*(1,2)*. Today, artificial intelligence (AI) technology is gradually becoming an important force in the medical development field*(3)*. At the same time, the ethical issues of medical artificial intelligence are becoming increasingly prominent. Although the prospects provided by artificial intelligence in the medical field are very promising, we need to control its use to avoid potential dangerous drift in this sensitive field*(4-6)*.

To find the key ethical concerns about medical artificial intelligence, the author searched for the topic of “medical artistic intelligence ethics” in the Web of Science database, and he obtained over 500 relevant literature (1975-2023). Then, a keyword co-occurrence map was drawn using VOS viewer 1.6.18 software (Figure 1). As shown in the figure, it indicated that issues such as privacy, autonomy, and responsibility have become key topics in medical artificial intelligence ethics research. The transparency issue of algorithms is an important node connecting thematic clusters such as “ethical principles” (yellow), “algorithm models” (red), and “medical practices” (blue). This indicates the algorithm transparency has become a key ethical question in the field of medical artificial intelligence

This article focuses on the algorithm transparency issue of medical artificial intelligence. The meanings and characteristics of the algorithm black box are introduced first. Later, both the ethical challenges and the solutions are analyzed. Then, combining with the current global ethical research trends of moral pluralism and monism, referring to specific cases in medical artificial intelligence research and application in recent years, it proposes a hybrid ethical design approach to address the algorithm black box problem.

The Algorithm Black Box and Ethical Challenges of Medical Artificial Intelligence

The application of artificial intelligence in the medical field is developing rapidly, AI technology relies on its powerful machine learning capabili-

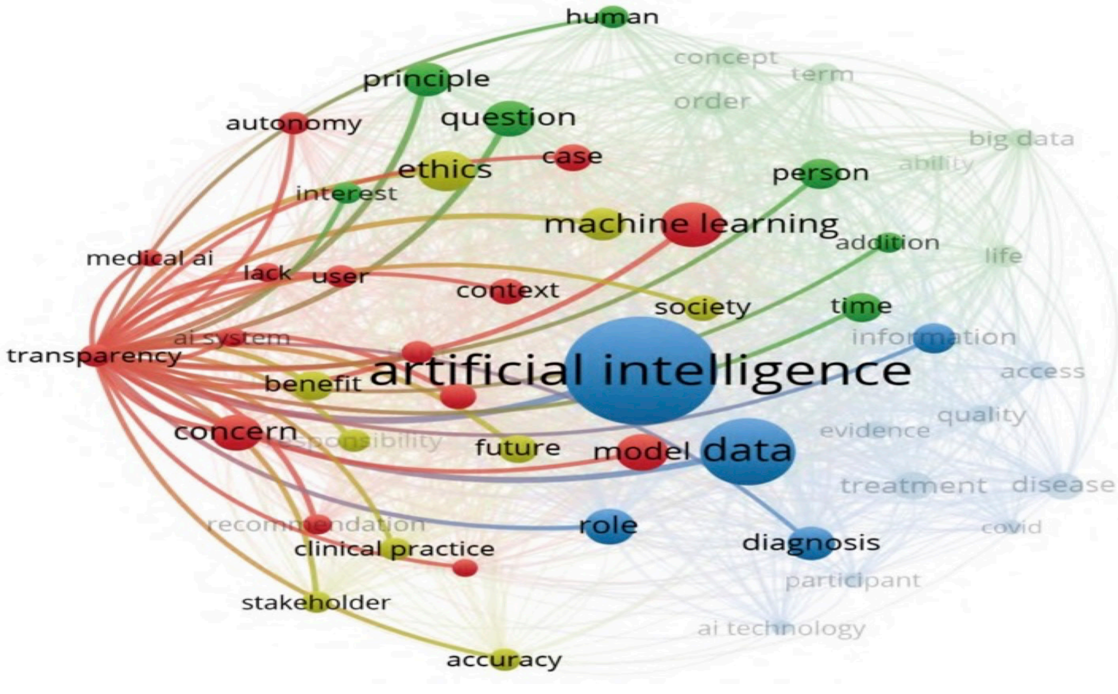

Figure 1: Literature keyword co-occurrence map on topic of “medical artificial intelligence ethics”. Web of Science database/VOSviewer

ties to have a certain degree of autonomy, but this also leads to the problem of lack of transparency in algorithms. Specifically, after extensive training, the internal state of the model becomes quite complex, and the operations between input and output are automatic. This makes it difficult for people to accurately predict the behavior of the algorithm and understand the mechanism. Therefore, people refer to this phenomenon as the "algorithmic black box" problem*(7,8)*.

For ordinary human doctors, modern medicine emphasizes experience and evidence. The examination and diagnosis process in diagnosis and treatment activities are a set of empirical deductions based on the causal relationship between phenomena and results. The diagnostic and treatment measures taken are also based on long-term repeated clinical experience summaries.

In contrast, for medical Artificial Intelligence, the deep learning algorithms used in diagnostic and therapeutic are essentially a set of statistical mathematical models. The input and output layers are more based on a certain probability correlation rather than causal relationships. Algorithms can extract certain correlations by processing massive amounts of data to provide treatment plans.

This means that artificial intelligence can provide accurate diagnostic and therapeutic judgments, but cannot explain how these judgments are made. In other words, the decision-making process is difficult to understand. Medical personnel can only verify these judgments based on observational data rather than clinical trials. This opacity of interpretability is not intentionally created by humans, it is an inherent attribute of the algorithm's technical logic. The algorithm is a complex architecture when processing massive amounts of data.

The internal state of the algorithm becomes quite complex, and the operations between input and output are automatic. This also makes it difficult for people to understand the mechanism. This leads to black box issues.

The algorithm black box brings a lot of confusion, people always hope for the transparency of the algorithm.

At present, in the field of machine learning, to solve the algorithm black box problem, some researchers have developed several interpretable tools to improve the transparency and interpretability of algorithms. For example, local interpretable model agnostic interpretations (LIME) technology can help humans understand the classification criteria in image recognition models; Shapley value can be used to describe the contribution of each feature value to the model prediction results, and thus to improve the interpretability of the algorithm.

However, in the field of medical artificial intelligence, interpretable models are rarely used. There are many reasons for the problems. On the one hand, the medical profession itself is profound, and on the other hand, artificial intelligence algorithms are also profound. For Medical Artificial Intelligence, comprehensive knowledge and skills are required develop the local interpretable model agnostic interpretations (LIME) technology. This increases the difficulty to develop such technologies. From the actual effect perspective, a lot of such models are unable to provide truly satisfactory explanations in clinical practice*(9,10)*.

There are many "black box" issues in medical care. Medicine itself is full of unknowability, and we have accepted various black boxes in medicine. For example, electroconvulsive therapy is very effective for severe depression, but we do not know how it works; Many drugs seem to be very effective, but no one can provide an appropriate explanation*(11,12)*. Moreover, the judgments of human doctors are not always interpretable. In many cases, the diagnosis of human doctors is based on experience, intuition, and even speculation, rather than understanding the mechanisms of the disease. In other words, sometimes, human doctors themselves do not know the mechanism when diagnosing.

The opacity could bring about danger, for the risks brought about by the algorithmic black-box, we can divide them into the following categories, as shown in Tab.1.

Table 1. Ethical matrix analysis of algorithmic black-box of medical AI

moral bodies	**Data ethics**	**algorithm ethics**	**social ethics**
Internal hierarchy (algorithm expert)	data abuse	intellectual property	discrimination and bias
Internal and external interaction levels (medical experts)	data misuse issues	autonomy issues	responsibility attribution issues
External level (patient, public)	privacy violations	security issues	information cocoon issues

The moral responsibility persons include three groups: Internal level (algorithmic experts), Internal and external interaction level (medical experts), and External level (patient, public). In the following, we discuss their ethical risks from the perspectives of data, algorithms, and society.

In terms of data dimension, the performance of machine learning is highly dependent on the quantity and quality of the dataset. There are differences in the understanding and utilization of data among different groups. This leads to ethical issues, and affects the accuracy and safety of artificial intelligence's medical decision-making.

For example, the medical artificial intelligence companies use the full information patient data, it could cause data abuse. The patient´s privacy rights are violated.

On the issue of data sharing, many companies are unwilling to share their key data, which affects the accuracy and safety of artificial intelligence's medical decision-making. As of 2022, the US Food and Drug Administration has approved over 200 machine-learning algorithms for clinical practice. However, most of these algorithms lack sufficient data validation to evaluate model performance*(13,14)*. This may lead to data misuse issues characterized by "garbage in, garbage out".

In terms of algorithms, programs developed by experts should be protected by intellectual property rights, and some algorithms may even be classified as confidential for security reasons. This conflicts with transparency. In other words, it increases the opacity. When patients are unable to understand the raw information of the data and model, they will question the safety of the product naturally.

The algorithm black box can also threaten the autonomy of doctors in diagnosis and treatment, that is, the medical artificial intelligence, which should be used as an auxiliary means, may lead to doctors overly relying on it. When doctors do not understand the mechanism of artificial intelligence algorithms, it is difficult for them to make modifications and adjustments to AI medical decisions. Then, doctors can only rely on the diagnosis and treatment decisions provided by algorithms. In fact, many doctors report that the IBM Watson diagnosis and treatment system often provides confusing medication recommendations, and even some treatment plans are quite dangerous for specific patients. However, doctors cannot "inquire" the algorithm´s black box about why it makes such unreasonable decisions*(15)*, and some inexperienced doctors may blindly accept the advice given by medical artificial intelligence and cause misdiagnosis.

In terms of the social dimension, it is possible for algorithmic companies to use black boxes to make the public unconsciously accept algorithmic control. However, due to differences in technical literacy between algorithmic experts and the public, an information cocoon is formed, making it even difficult to achieve a transparent algorithm. Due to the opacity of the algorithm black box, it is difficult for people to detect and correct the biases and discrimination that may be included in the model, which in turn can pose a threat to the health of patients*(16)*. In addition, the joint participation of doctors and medical artificial intelligence in the medical decision-making process can make the issue of responsibility attribution particularly complex: who should be responsible for errors in diagnosis and treatment? The algorithm developer or the doctor? For this question, the opinions of the public and doctors are different. a survey targeting the American public shows that when medical artificial intelligence causes medical accidents, the public (66.0%) is more inclined to believe that the doctor is the main responsible party, while doctors (43.8%) are more inclined to believe that the provider of artificial intelligence products should bear the main responsibility*(17,18)*. However, with the development of artificial intelligence technology, it is still necessary for us to consider how to make artificial intelligence systems have moral judgment ability to cope with the social risks and ethical challenges.

The ethical design approaches

The algorithm black box problem has become the current key ethical challenge in the field of medical artificial intelligence. The development of artificial intelligence with autonomous moral judgment ability, that is, the construction of artificial moral agents (AMAs), has been looked at as a feasible solution to resolve ethical issues. It means that AMAs have basic moral reasoning and moral judgment abilities.

This plan attempts to avoid the ethical risks that may be brought about by algorithmic black boxes by incorporating the paradigm of ethical into the research and development process. It enables artificial intelligence systems to have the ability to mitigate ethical risks.

How to develop artificial intelligence with autonomous moral reasoning capabilities?

Currently, many scholars have put forward some approaches to achieve AMAs*(19,20)*, those solutions can be divided into two categories: Top-down approach; Bottom-up approach.

However, according to the author's viewpoint, both top-down and bottom-up approaches have too limitations. In order to resolve the ethical challenges caused by the black box, the hybrid ethical design approach that combines "top-down and bottom-up" should be more reasonable.

1. Limitations of the top-down and bottom-up approaches

The top-down approach refers to the design of medical artificial intelligence ethical agents based on specific ethical principles to achieve a transparent and interpretable medical artificial intelligence system. Many scholars and institutions have proposed various norms and initiatives regarding ethical design for medical artificial intelligence. For example, in the "Ethics and Governance of Artificial Intelligence in the Health Sector" guidelines released by the World Health Organization in 2021, "ensuring transparency, interpretability, and comprehensibility" is one of the basic ethical principles that medical artificial intelligence should follow, and requirements are made for the transparency of relevant information such as technical limitations, operational records, data properties, and algorithm models*(21)*. However, the effectiveness of this top-down approach is quite limited, and the problem is that these preset ethical principles sometimes are hard to respond appropriately to complex ethical situations.

Firstly, as an emerging discipline, medical artificial intelligence inherently lacks a certain degree of ethical consensus among experts. There is a divergence between moral individualism and holism among data scientists. The former believes that facts and values are independent and they should adopt a technically neutral stance, while the latter believes that facts and values are inseparable and they believe that the ethical risks of artificial intelligence technology should be controlled strictly.

On the other hand, among ethicists, it is also difficult to form a consensus on what ethical principles should be adopted. In situations where there are conflicts between different principles, the rationality of using which set of ethical frameworks to guide the design of medical artificial intelligence may be questioned. For example, the principle of transparency requires medical artificial intelligence to be subject to scrutiny, but the principle of privacy protection requires it to keep data information confidential. Thus, the ethical dilemma caused by the top-down approach will bring more challenges to designers.

Secondly, there may be a contradiction between the ethical principles and practical goals of medical artificial intelligence, and achieving transparency often requires sacrificing a certain degree of accuracy. For example, during surgery, anesthesiologists need to monitor many physiological indicators to adjust the depth of anesthesia, and these physiological indicators often have linear relationships. Based on this fact, some scholars have developed a machine-learning algorithm that uses gradient descent to build a regression model to achieve automatic regulation of anesthesia. This is a highly understandable algorithm; However, in clinical practice, this algorithm cannot provide the best dose recommendation.

While, other algorithms based on neural networks perform better, although they have lower transparency. Do we need accuracy and security, or comprehensibility and transparency? The top-down approach does not provide a suitable answer.

Finally, when we face an environment with multiple moral standards, the ethical principles are difficult to provide us with specific guidance. When the designers design a logically monotonous moral reasoning algorithm for medical artificial intelligence based on the principle of transparency, the first problem is how this algorithm to matches the diverse persons, the diverse moral standards in different communities and cultures. For example, manufacturers, doctors, and ordinary users have different purposes and different cognitive abilities. On the other hand, the ethical principles are often too abstract and lack a certain degree of flexibility, they are hard to implement in the design of medical artificial intelligence.

The top-down approach make it difficult to fully consider the comprehensibility standards of differences, so this approach still cannot resolve the ethical risks of algorithmic black boxes.

To achieve AMAs, some scholars support other approaches, which is called the "bottom-up approach". This approach does not require engineers to follow a set of established ethical principles to design artificial intelligence, but rather allows the artificial intelligence to autonomously evolve a set of operating methods that conform to human moral standards in a series of reinforcement learning scenarios based on specific cases. In other words, it is to enable artificial intelligence to evolve a set of ethical systems that are in line with human standards through autonomous learning.

However, according to the author's viewpoint, relying solely on this approach cannot solve the ethical issues brought about by the algorithmic black box.

Firstly, the bottom-up approach, as a means of regulation and adjustment after the fact, needs to constantly learn and evolve. During its trial and error process, the negative moral consequences generated cannot be avoided.

Secondly, there are differences in moral standards, views, and behaviors among different individuals. The artificial intelligence machine's imitation of human moral behaviors is difficult to form a unified moral reasoning framework. For example, diagnostic and therapeutic robots may not be able to recognize the concealment and deception of the medical history of patients with mental disorders in their speech during training.

Thirdly, the bottom-up approach may allow medical artificial intelligence to learn some behavior patterns that violate moral standards due to the lack of guidance from ethical principles. Human beings do not know what behaviors artificial intelligence will evolve through learning, this actually increases the opacity of algorithms.

Therefore, the bottom-up approach cannot successfully build a medical artificial intelligence moral body that meets our requirements, and the ethical problems caused by the algorithm black box still cannot be resolved.

In summary, both top-down and bottom-up approaches have significant limitations.

2. Prospects of the hybrid ethical design approach

According to the author's viewpoint, a "hybrid approach" that combines both top-down and bottom-up can better cope with medical artificial intelligence algorithms ethical challenges brought by black boxes.

The hybrid ethical design approach requires engineers to set a certain elastic ethical framework for medical artificial intelligence through a top-down approach, and embed more ethical moral requirement design into the entire process of medical artificial intelligence research and development*(22,23)*, the ethical framework only contains the most basic ethical principles. At the same time, it should consider the different moral environments in the process of learning evolution.

It also adopts a bottom-up approach, allowing the algorithm to learn human moral behavior patterns, giving full play to the advantages of medical artificial intelligence in processing multi-situational information, let it develop multiple moral reasoning models. What's more, the content of the ethical framework can be adjusted appropriately based on the learning and evolutionary process.

At the same time, we should note that in the ethical design of artificial intelligence, the following two mandatory requirements need to be added.

Firstly, some important algorithm source codes should be mandatory to open under certain conditions. We know, at present, the source code of the Windows system has always been confidential, and it is difficult for other experts to repair and remedy Windows system. Similarly, in the future, highly artificial intelligent systems will appear, if the algorithm source codes are in secret, it would be difficult for other experts to fix the vulnerabilities. And it may be difficult for other experts to control the system. If such a situation occurs, it could bring bad things for human beings. On the other hand, to protect intellectual property rights, a public interest organization would be established to receive and store those source codes, only under some specific circumstances, could the source codes be used.

Secondly, the most basic ethical principles should be forcibly embedded in artificial intelligent systems. For example, "No harm" is the most basic moral principle for doctors. It should be forcibly embedded in AI systems. Doctors have a moral obligation not to cause unnecessary harm. It means doctors have a moral obligation not to cause both the unnecessary physical bodily injury and economic injury. For the artificial intelligence systems, it is the same. From a social perspective, let us suppose, for example, that powerful artificial intelligence systems have the ability of intentionally harming to the general population, at the same time, they are controlled by only several persons, if those persons control the powerful AI systems to do wrong things. It would be of ethical failure.

Early researchers still adopted a computational stance, they believed that artificial intelligence only had the mechanical ability to perform moral computation, and could not form true moral reasoning abilities.

With the continuous advancement of ethical research in artificial intelligence, the ethical design approach has achieved theoretical breakthroughs. For example, some scholars have elaborated on the specific process of embedding human values into artificial intelligence systems*(24,25)*. At the practical level, some scholars have gradually shifted from limited machine training in early laboratory environments to handling moral dilemmas in the real world. That is to say, artificial intelligence has had moral judgment abilities, and such abilities are becoming stronger and stronger.

However, some scholars think that artificial intelligence does not need moral reasoning ability or moral judgment ability. Artificial intelligence technology is only neutral, it is a matter of human beings about how to utilize it. They think what we need is a safer and accurate artificial intelligence, rather than an ethical artificial intelligence.

However, according to the author's opinion, in today's information society, the various value systems and cultures are spreading globally, the conflict and integration cannot be avoided. The ethical challenges faced by artificial intelligence are becoming increasingly complex. It requires us to reflect on the ethical issues of artificial intelligence. According to our viewpoint, due to the increasing power of artificial intelligence, it is reasonable to equip it with basic moral judgment abilities. The hybrid approach could achieve this goal.

In the field of life medicine, people have basic moral requirements for artificial intelligence. The hybrid approach could meet this need. Firstly, contrary to traditional moral monism, moral pluralism supports that moral decision-making in medicine is complex and diverse, and different subjects have different expectations for the moral behavior of artificial intelligence in different situations. A hybrid approach can respond to moral differences in the real world better. secondly, moral contextualism opposes the absolutist stance on morality within the framework of normative ethics, emphasizing that the criteria for comprehensibility and transparency are strongly related to the situation in which people are located, and there is no single criterion. The hybrid approach provides a value alignment path for resolving algorithmic black box ethical problems, which can align the moral behavior of medical artificial intelligence with the value judgments of stakeholders. finally, this approach follows the reflective equilibrium method in moral philosophy. Based on the practical goals of medical artificial intelligence, it identifies the ethical challenges and continuously adjusts according to the actual situation on the basis of formulated moral principles. This enables medical artificial intelligence to respond to complex moral issues and better meet people's needs for safety and accuracy.

From the internal perspective of medical artificial intelligence algorithms, hybrid ethical design requires algorithm engineers to consider the transparency of the algorithm at the beginning of the design. On the one hand, by developing interpretability tools that are separated from the underlying machine learning model, we can avoid the ethical difficulties that may arise from algorithmic black boxes. For example, when algorithm engineers build a machine learning model for neuroimaging, they add a tool that supports prediction, complementary procedures of verification and interpretation, evaluate the impact of interference in the model, and indicate possible discrimination and bias contained in the black box of the algorithm. This can improve the transparency.

For deep neural networks that analyze medical images, methods to improve the interpretability of the algorithm include concept learning models, counterfactual explanations, internal network representations, etc.

On the other hand, the hybrid approach requires engineers to build algorithms with self-explanatory capabilities. This can help to open the black box.

In addition, we can adopt many information technologies to visualize patient data, providing medical artificial intelligence with a more intuitive human-computer interaction interface and improving the comprehensibility of algorithms. Thus, the transparency of both the algorithms and the decision-making processes can be improved.

From the external perspective of the medical artificial intelligence algorithms, the hybrid approach requires all stakeholders to participate in the algorithm design process to resolve the problem of the algorithm black box. At present, some medical artificial intelligence developers have integrated doctors and patients into the algorithm design process.

A team developed an algorithm to evaluate treatment options, it included patients and doctors in the research of the algorithm design. It solicits opinions on transparency and understandability; this can ensure the autonomy of the patients. Medical experts can not only assist algorithm engineers in handling labels and supervised learning, but also play a key role in model validation. For example, some researchers have used a moral reasoning neural network called "Delphi" to process the opinions and consensus of medical experts. This algorithm can adjust its comprehensibility on time based on the clinical practice of doctors. The open participatory research in the algorithm design stage can improve the algorithm transparency. It can help build a "humanistic" medical artificial intelligence moral system, so that medical artificial intelligence can protect human dignity and subjectivity, at the same time, it can enable developers to assume corresponding moral responsibilities.

In summary, adopting a hybrid ethical design approach can make medical artificial intelligence learn moral reasoning in real-life situations and develop moral models embedded in its own algorithms. It allows medical artificial intelligence to effectively deal with conflicts between different ethical principles, and adapt to moral needs in practical applications. It can avoid the difficulties caused by the rigidity of the top-down approach. In addition, the hybrid approach advocates for the widespread participation of multiple stakeholders, which can help medical artificial intelligence better handle complex moral scenarios, and align its behavior in different cultures.

It should be pointed out that in terms of the current development status of artificial intelligence, the hybrid approaches can only achieve relatively limited comprehensibility, and the algorithm black box cannot be completely "solved "in the short term. In addition, there are still many controversies about whether artificial intelligence systems can possess consciousness and free will. Those controversies make it difficult for AI to obtain a complete moral subject status. Based on this, the "algorithmic gray box" design with local interpretability can achieve a good balance between accurate "black boxes" and transparent "white boxes", which meets the moral judgment ability demands of medical artificial intelligence. For example, some studies have extracted classification information from brain cancer images using convolutional neural networks, and then extracted feature information such as the location and size of brain cancer from medical history, combining, them to improve the interpretability of brain cancer diagnostic models.

In the process of developing medical artificial intelligence moral system, through this hybrid approach, it is possible to combine the advantages of both top-down and bottom-up approaches. It can respond better to more complex ethical challenges in medicine.

Conclusion

Artificial intelligence technology is leading the transformation in the field of healthcare, and the algorithmic black box has brought significant ethical challenges to the development of medical artificial intelligence. Resolving the ethical challenges of algorithmic black boxes and building a medical artificial intelligence ethical system not only requires the participation of algorithm engineers, companies, governments, doctors, patients, ethicists, and other parties to provide ethical principles with a certain consensus for the design of medical artificial intelligence but also requires setting functional ethical status for medical artificial intelligence, to ensure its behavior and value framework are in line with human comprehensibility and autonomy. With the hybrid approach, moral design can better respond to the current societal demands for moral pluralism and contextualism can allow artificial intelligence to conduct moral reasoning and adopt appropriate actions based on diverse value systems and specific moral situations, thus promoting the innovation and development of medical artificial intelligence.

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Conflicts of interest statement

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Author contributions

Chen Hui put forward the idea; Hu Qinggu completed the first draft of paper and Kyle Michael James; Tang Xiuqiong and Wang Jinsong polished it and strengthened some parts of arguments.

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ETHICAL CHALLENGES RELATED TO CAPACITY, COMPETENCE AND AUTONOMY IN INDIVIDUALS WITH DEMENTIA

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Abstract: Dementia is a syndrome characterised by the development of multiple cognitive deficits and behavioural changes that significantly interfere with various aspects of life.

The study aims to discuss capacity, competence and autonomy in individuals with dementia, and some ethical challenges related to these concepts, such as healthcare decision-making capacity, financial capacity, driving and voting. Secondarily, we aim to discuss a new ethical issue emerging from using artificial intelligence and machine learning to improve autonomy in individuals with dementia. Furthermore, we will discuss the ethical importance of obtaining informed consent for healthcare decision-making and Advance Care Planning in dementia patients.

This study provides a comprehensive overview of the complex issues related to autonomy and competence in individuals with dementia, highlighting the importance of striking a balance between upholding individual rights and protecting the well-being of those affected by the disease. In conclusion, the study emphasizes the importance of Advance Care Planning in helping patients, families, caregivers, and healthcare professionals address ethical issues related to autonomy, capacity, and competence in dementia care.

Keywords: autonomy, capacity, competence, artificial intelligence, decision making, dementia

Desafíos éticos relacionados con la capacidad, la competencia y la autonomía en individuos con demencia

Resumen: La demencia es un síndrome caracterizado por el desarrollo de múltiples déficits cognitivos y cambios conductuales que interfieren significativamente con varios aspectos de la vida.

El estudio tiene como objetivo analizar la capacidad, la competencia y la autonomía en individuos con demencia, así como algunos desafíos éticos relacionados con estos conceptos, tales como la capacidad para tomar decisiones en salud, la gestión financiera, la conducción de vehículos y el derecho al voto. Secundariamente, buscamos abordar una nueva cuestión ética emergente del uso de la inteligencia artificial y el aprendizaje automático (*machine learning*) para mejorar la autonomía en personas con demencia. Además, discutimos la importancia ética de obtener el consentimiento informado para la toma de decisiones en salud y para la planificación anticipada de cuidados en pacientes con demencia.

Este estudio ofrece una visión integral de las complejas cuestiones relacionadas con la autonomía y la competencia en individuos con demencia, destacando la importancia de equilibrar el respeto por los derechos individuales con la protección del bienestar de las personas afectadas por esta enfermedad. En conclusión, subraya la relevancia de la planificación anticipada de cuidados para ayudar a pacientes, familias, cuidadores y profesionales de la salud a abordar cuestiones éticas relacionadas con la autonomía, la capacidad y la competencia en el cuidado de la demencia.

Palabras clave: autonomía, capacidad, competencia, inteligencia artificial, toma de decisiones, demencia

Desafios éticos relacionados com a capacidade, a competência e a autonomia em indivíduos com demência

Resumo: A demência é uma síndrome caracterizada pelo desenvolvimento de múltiplos défices cognitivos e alterações comportamentais que interferem significativamente com vários aspetos da vida.

O estudo tem como objetivo discutir a capacidade, a competência e a autonomia em indivíduos com demência, bem como alguns desafios éticos relacionados com estes conceitos, tais como a capacidade para tomar decisões em saúde, a gestão financeira, a condução de veículos e o direito ao voto. Secundariamente, propomo-nos abordar uma nova questão ética emergente do uso da inteligência artificial e do aprendizado automático (machine learning) na melhoria da autonomia em pessoas com demência. Além disso, discutiremos a importância ética de obter o consentimento informado para a tomada de decisões em saúde e para o planeamento antecipado de cuidados em pacientes com demência.

Este estudo apresenta uma visão abrangente das questões complexas relacionadas com a autonomia e a competência em indivíduos com demência, sublinhando a importância de equilibrar o respeito pelos direitos individuais com a proteção do bem-estar das pessoas afetadas pela doença. Em conclusão, o estudo enfatiza a relevância do planeamento antecipado de cuidados para ajudar pacientes, famílias, cuidadores e profissionais de saúde a enfrentarem questões éticas relacionadas com a autonomia, capacidade e competência no cuidado à demência.

Palavras-chave: autonomía, capacidade, competencia, inteligência artificial, tomada de decisão, demência

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Introduction

Autonomy, capacity and competence

The word 'autonomy' derived from the Greek words *autos* ('self') and *nomos* ('rule', 'governance' or 'law'), originally referred to the self-rule or self-governance of independent city-states*(1)*. It was exclusively applied in a political context. Some centuries later, autonomy was described by Jean-Jacques Rousseau, who defined autonomy as more than a mere lack of coercion from external influences *(2)*.

After Rousseau, Kant discussed autonomy in terms of man's moral character*(3)*. In this way, autonomy does not consist solely of independence in the face of sensitive inclinations but equally in the ability to act by a moral law without the mediation of categorical and insensate hopes, considering the limits of reason*(4)*. Kant conceived autonomy with two presumptions: firstly, morality is discerned from within oneself; and secondly, moral imperatives can be deduced from an a priori moral law, the categorical imperative, which tells us to act in a way that could be a universal rule*(5,6)*.

Raanan Gillon defined autonomy (literally, self-rule) as the capacity to think, decide and act based on one's thoughts and to decide freely and independently without any hindrance*(7)*. He concluded that autonomy is a subclass of freedom or liberty. However, not all forms of freedom or liberty can be considered autonomous. In this sense, the author explained that autonomy is necessary for human beings to maintain their full quality of life and, in a certain sense, their complete freedom*(7)*.

Gillon describes three types of autonomy: a) autonomy of thought, b) autonomy of will and c) autonomy of action. Autonomy of thought encompasses a wide range of intellectual activities that are referred to as 'thinking for oneself', including decision-making, forming beliefs, expressing preferences and making moral assessments. Autonomy of will, or autonomy of intention, is the freedom to decide to do things based on one's deliberation. Autonomy of action is the physical ability to act*(7)*.

Beauchamp and Childress analysed autonomous action in terms of three conditions: intentionality, understanding and non-control. *Intentional* actions require plans in the form of representations of the series of events proposed for the execution of an action with intentionality. An action is not autonomous if the actor does not adequately understand it (*understanding*), and the person must be free of any controls exerted either by external sources or by internal states that rob the person of self-directedness (*non-control)(1)*.

Autonomy diverges from the principle of respect for autonomy. Beauchamps and Childress highlight that the principle of respect for autonomy encompasses both negative and positive obligations. As a negative obligation, it requires that autonomous actions not be subjected to controlling constraints by others. As a positive obligation, the principle emphasizes respectful treatment in disclosing information and actions that foster autonomous decision-making *(1,8)*.

If autonomy is a relevant philosophical concept, capacity is essentially a practical concept. Hedge and Ellajosyula define capacity as a person's ability to make a particular decision at a specific time or in a certain situation*(9)*. In a clinical context, capacity refers to a set of cognitive functions such as memory, judgement and decision-making required to manage one's affairs and perform everyday tasks *(10)*.

Moye and Marson argue that eight major capacity domains are relevant to older persons: a) consent to medical treatment, b) independent living, c) financial capacity, d) consent to research participation, e) testamentary capacity, f) voting, g) sexual consent and h) driving. In each of these domains, there are specific issues in which a person's incapacity in one domain may not affect another domain*(11)*. In other words, capacity evaluates a specific act at a given time*(9)*.

In practical scenarios, healthcare professionals often engage in discussions about a patient's capacity. They assess whether cognitive impairment affects the ability to effectively make decisions, especially in the domains of consent to clinical treatment, independent living and financial capacity*(12)*. Additionally, they evaluate capacity to determine if an individual has the competence to handle these tasks.

Regarding competency, Fellows states, ‘If capacity can be explained as a pragmatic concept, referring broadly to the ability to consent, competency is a legal term’*(13)*, and Marson concluded that competency concerns an individual’s legal capacity to make certain decisions and to perform certain acts*(14)*. Moreover, there is a presumption that adults can exercise choices and make decisions for themselves until proven otherwise*(14)*.

Once the capacity of an individual has been assessed, it is possible to evaluate whether they possess competency. However, in practice, both factors are evaluated together, and some experts consider them to be the same concept*(15)*. As stated by Beauchamp, competence is the ability to perform a task*(1)*. The author justifies this position by noting that when clinicians judge that patients lack decision-making capacity, the practical effects of these judgments may not differ from those of a legal determination of competence*(1,15)*.

Although there is a connection between capacity and competence, clinical practice assessments and legal evaluations do not always share the same objectives. Therefore, it is essential to differentiate between these terms, and in this article, capacity and competence will not be used synonymously.

Determining competence is important in clinical settings, particularly concerning the informed consent (IC) form, which assesses the patient’s ability to make decisions. Informed consent is the process in which a healthcare provider educates a patient about the risks, benefits, and alternatives of a given procedure or intervention*(16)*. For consent to be legally valid, the patient must be fully informed and capable of understanding the information, make a voluntary choice and have decision-making capacity*(17)*, namely the competence to sign or declare their will in the IC.

In the field of bioethics, autonomy, capacity and competence are upheld. There are two important documents, namely The Universal Declaration on Bioethics and Human Rights*(18)* and The Convention for the Protection of Human Rights and Dignity of the Human Being about the Application of Biology and Medicine: Convention on Human Rights and Biomedicine*(19)*, which emphasise the need to protect the interests of individuals who may be incapable of making their own decisions.

In accordance with Article 7 of The Universal Declaration on Bioethics and Human Rights*(18)*, domestic laws must provide special protection to individuals who lack the capacity to consent. This includes obtaining authorisation for research and medical practice in the best interest of the individual and according to domestic law. However, the person concerned should be actively involved in the decision-making process regarding giving or withdrawing consent to the greatest extent possible.

Similarly, The European Convention on Human Rights and Biomedicine (Articles 6 and 17)*(19)* states that if an adult cannot consent to intervention due to mental disability, disease or similar reasons, the intervention may only be carried out with the authorisation of his/her representative or an authority, person or body provided by law.

Dementia

Currently, more than 55 million people worldwide are affected by dementia, and it is expected that this number will triple by 2050*(20–23)*. Moreover, dementia is a significant burden for both individuals and society. Recent studies analysing data from 17 European countries estimated that the average dementia care costs for all patients varied by region. The costs were highest in the British Isles (73,712 EUR), followed by the Nordics (43,767 EUR), Southern (35,866 EUR), Western (38,249 EUR) and Eastern Europe and the Baltics (7,938 EUR)*(24)*. Due to its high prevalence, expensive costs and complex care requirements, dementia presents a significant challenge for public health systems worldwide.

Dementia, or major neurocognitive disorder, is characterised by a significant decline in one or more cognitive domains from one’s previous level of ability, that interferes with everyday functioning*(25)*. Dementia should be considered a syndrome with multiple possible causes rather than a specific disease itself*(22)*.

Dementia is a progressive disease that impacts an individual’s ability to perform tasks as time goes on. While those in the early stages of the disease can typically manage most tasks, the later stages can lead to a loss of autonomy, capacity, and competence, making individuals more dependent*(22)*. As the disease progresses, ethical debates arise around the capacity and competence to perform tasks such as healthcare decision-making, financial capacity, driving, and voting.

There are several causes of dementia. Alzheimer's disease is the most common cause of dementia, accounting for an estimated 60–80% of cases*(27)*. Other common causes include vascular dementia, Lewy body disease, frontotemporal dementia and mixed dementia*(26,27)*. Each type of dementia has different symptoms and progressions, which can affect certain abilities more than others.

Dementia imposes emotional and physical burdens on caregivers and families involved in patient care*(28,29)*. The burden increases over time, and the clinical characteristics of patients (including neuropsychiatric symptoms, patient dependence and functional decline), level of services and caregiver gender appear to be the best predictors of this burden*(28–31)*. Healthcare professionals, caregivers, and families are seeking alternatives to reduce costs and burdens associated with caring for people with dementia while improving their autonomy.

Artificial intelligence (AI) and machine learning (ML) are now offering automated solutions to enhance autonomy for individuals with dementia. AI and ML have the potential to improve the lives of individuals with dementia in several ways. This includes cognitive screening and training, diagnosing and predicting dementia, as well as providing care and interventions for dementia*(32–34)*. The use of AI and ML in the context of dementia is directly related to increasing patients' independence and autonomy and improving the quality of life for patients, their families, and caregivers*(35)*. However, these news tools raise ethical and legal concerns that need to be addressed.

The purpose of this article is to discuss capacity, competence and autonomy in individuals with dementia, and some ethical challenges related to these concepts, such as healthcare decision-making capacity, financial capacity, driving and voting. Secondarily, we aim to discuss a new ethical issue emerging from using artificial intelligence and machine learning to improve autonomy in individuals with dementia. Furthermore, we discuss the bioethical relevance of informed consent (IC) and advance care planning (ACP) in dementia disease.

Ethical issues in dementia

1. Healthcare decision-making capacity

Decision-making capacity is at the core of ethical issues in dementia, involving autonomy, capacity and competence. It is impossible to conceive an autonomous person without some level of decision-making capacity. Decision-making covers a wide range of areas, but for this article, we will focus on healthcare decision-making capacity. This capacity does not differ from the general ability to make decisions but is rather encompassed by it.

The most critical instrument in healthcare decision-making is the inform consent (IC) form for medical treatment. It is an ethical and legal obligation for patients to be capable of providing consent. Therefore, a valid IC must be given by someone who can make decisions.

Appelbaum and Grisso describe the general competence criteria for making IC*(36)*: a) the ability to communicate choices; b) the ability to understand information about treatment decisions; c) the ability to appreciate the situation and the consequences; and d) the ability to use logical processes to compare the benefits and risks of various treatment options*(36)*. All these criteria must be met by individuals with dementia.

2. Financial capacity

The capacity for financial decision-making can be defined as 'the capacity to manage money and financial assets in ways that meet a person's needs and align with their values and self-interest'*(37)*. Financial decision-making capacity is a critical skill for maintaining an independent life, and it is linked with capacity, autonomy and competence.

If healthcare decision-making capacity is perhaps the main concern of healthcare professionals, financial capacity is a significant concern for dementia patients and their families. In addition to issues related to obtaining IC, individuals may face difficulties in financial management since the onset of the disease, leading to potential financial losses that may go unnoticed even by close family members*(11,38)*.

Once identified, the reduction in financial capacity significantly impacts patients' lives*(38-40)*. Difficulties with shopping, managing money, paying bills, and other daily financial tasks diminish the patient's autonomy, forcing families to limit the patient's competence to prevent financial losses*(37-40)*. Reduced financial capacity not only decreases the patient's autonomy but also progressively impairs their competence.

Families are mainly concerned with avoiding financial losses, but healthcare professionals also need to be vigilant about potential exploitation and abuse by family members or others*(37,38)*. To prevent these issues, healthcare professionals should prompt patients to engage in advance care planning and make decisions about proxies in the early stages of the disease when they are able to do so*(37,38)*. Additionally, they should involve public agencies and social support organizations to assist and care for these patients*(41)*.

The advancement of specific technological tools, such as artificial intelligence, can help patients with dementia improve their financial capacity and independence*(42)*. Tools are being developed, such as virtual financial assistants, that manage payment systems and shopping, prevent losses, and enhance patient autonomy. The use of the Internet of Things (IoT) and mobile computing to address issues related to impaired financial capacity is a good example. Monitoring financial transactions, gathering real-time biometric data, and sending alerts to professionals or caregivers are just a few of the ways that the IoT can be used to support the well-being of individuals with dementia*(43)*.

3. Driving

Driving is associated with an independent life, enabling daily problem-solving and social interaction through mobility. For many older individuals, ceasing to drive can result in a loss of autonomy. However, the inability to drive can also pose significant risks for both the driver and others on the road. While older individuals with normal cognitive functions may experience some difficulties, the discussion becomes more complex when it comes to those with dementia*(44–46)*.

Driving ability spans multiple cognitive domains, requiring visuospatial skills, executive function, memory, attention and motor skills*(47)*. The assessment of cognitive, physical, and psychological factors is crucial for evaluating driving capacity and determining who is fit to drive and who may not be*(48)*.

There is an important intersection between capacity and competence in driving. In most countries' legislation, physicians have the authority to determine who is fit to drive. Once visual, hearing and attention problems are identified, professionals must inform the competent authority to revoke the driving licence*(46,49,50)*.

In this case, the challenge is not the patients' assessment of driving ability but the opportunity to evaluate cognitive impairment in patients earlier. Sometimes, in the early stages of dementia, it is not possible to evaluate patients before a burdensome event occurs. A driving crash can highlight cognitive problems, serving as an opportunity to make a dementia *(51)*.

4. Voting

Although voting may not be a critical issue for families of dementia patients, the possibility of voting is a significant milestone of citizenship. The vote is a universal right for most countries, and even if it is not directly related to autonomy or capacity, it is an important landmark of full competence.

To assess voting ability, most studies demonstrate a strong correlation between dementia severity and the capacity to vote*(52–54)*. The studies clarify that in severe dementia, the capacity to vote is compromised, while in most cases of mild dementia, it is preserved. In moderate dementia, an individual evaluation is necessary because the response is not clear.

The specificity of the ability to vote is that if dementia patients do not undergo a legal procedure to reduce their competence, even patients who lack the capacity for decision-making can still vote, as it is impossible to prevent them from doing so.

Karlawish et al., analyzing the American election system, identified three critical issues related to voting for people with dementia: the need to develop a method to assess the capacity to vote, identify appropriate types of assistance for individuals with cognitive impairment to vote, and create consistent policies for voting in long-term care settings*(55)*. These issues could also be considered by other countries.

The assessment of voting ability in individuals with dementia should adhere to the same general competence criteria required for giving informed consent: understanding, choice, reasoning, and appreciation. Appelbaum et al. developed a specific assessment tool for voting, evaluating if the person can understand the nature and the effect of voting, can make a choice, can engage in comparative reasoning, and is aware of the potential consequences and appreciation*(56)*.

The issue of voting competence for individuals with dementia requires specific legislation to determine if they are capable of voting and how to support them if they are able to do so. This complex topic involves patients, families, caregivers, healthcare professionals, and public health policy.

5. Artificial intelligence to improve autonomy in individuals with dementia

Artificial Intelligence (AI) is a term coined in 1956 that refers to the ability of computers to mimic intelligent human behaviour with minimal human intervention*(57)*. It is a vast field of computer science that involves creating machines, systems or software that can perform tasks that typically require human intelligence. One of the subfields of AI is machine learning (ML), which focuses on developing algorithms and statistical models. These algorithms and models enable computers to improve their performance on a specific task through data analysis without requiring explicit programming*(34,57)*.

AI and ML can improve individuals' autonomy, such as through the use of AI robots that can assist individuals with dementia in daily tasks and with sensors around the house that can intelligently monitor a person's behaviour*(58)*. ML algorithms have been successfully employed to automatically discriminate Alzheimer´s disease (AD) from vascular dementia (VD), reaching a classification accuracy greater than 84%*(59)*.

The topic is new and not fully discussed in the literature. For instance, there is an ethical debate surrounding AI devices that monitor and record individuals with dementia in their private lives and using care robots can create conflicts with ethical principles. The authors emphasize the tension between older adults' autonomy and privacy*(60)*. Older adults and caregivers may not be aware that robots are recording them and that these recordings may be shared with others. While these devices can enhance autonomy, prevent dangerous situations, and promote human welfare, it is unclear whether they adhere to ethical principles*(60-62)*.

The literature highlights several ethical principles and values associated with AI and ML in patient interactions that should be respected to ensure ethical practices. Among these, the principle of non-maleficence (prevention of harm) is the most explored. Other prevalent principles include self-determination, promoting human welfare, and privacy*(60–62)*.

Non-maleficence is the ethical principle of "no harm." AI systems should be designed and developed not to undermine or harm people*(61)*.

The self-determination principle refers to the right of individuals to make their own choices and decisions. This principle emphasizes autonomy and personal freedom, allowing people to control their own lives and make decisions that affect them without undue influence or coercion*(63,64)*. Remmers points out that the reduction of independence does not automatically result in an incapacity of self-determination*(63)*. According to this author, the longest possible preservation of self-determination is the main normative background legitimising the usage of assistive technologies in the home*(63)*.

Promoting human welfare involves actions and policies to improve individuals' and communities' well-being and quality of life. Welfare technologies is supposed to give better and more focused care, reduced risk and increased safety, increased coping and self-determination, make it possible to stay at home longer, avoid harm (from falling, fire, robbery), make more just resource allocation, and to promote technology development, commercialization and growth*(63-65)*.

Privacy is the right of individuals to keep their personal information and activities from being disclosed or accessed without their consent. It provides protection by maintaining confidentiality and respecting sensitive information. This is crucial, especially in contexts like healthcare, where patient data must be safeguarded. Various types of Intelligent Assistive Technology could be used to access private and sensitive user-related information. Therefore, privacy and security breaches should be anticipated and prevented by technological developers*(63-66)*.

Discussion

How to address ethical issues related to dementia

Understanding the concepts of autonomy, capacity and competence, along with their ethical and legal implications, is challenging for clinicians, individuals living with dementia and their families. It is important to know how to cope with practical situations in daily life and nowadays in emerging fields of technology.

Due to the range of issues involved, some basic principles must be applied before an intervention or restriction to support someone in making their own decisions. They are as follows, a person: a) is presumed to have capacity; b) shall not be treated as unable to decide unless all practicable steps have been taken to help him or her do so; c) shall not be regarded incapable of making a decision merely by making an unwise decision; and d) shall not intervene unless it is necessary, considering the individual circumstances of relevant person*(67)*.

The principles mentioned above are universal. They are suitable for all cases of capacity restriction, including all types of dementia diagnoses.

Adults are presumed capable of making their own decisions, and any limitations to their capacity or autonomy should be viewed as an exception*(67,68)*. In cases where a person is deemed incapable of making decisions, it is important that the decision-making process still protects their best interests and does not cause them harm. To determine whether a person is incapable of making decisions, all necessary steps must be taken to evaluate both the individual and the situation*(67,69)*.

The investigation of whether individuals have the capacity and competence to provide IC, manage their finances, drive, vote or make decisions about using AI tools or participating in ML programs in the context of dementia follows a similar pattern. Nonetheless, there is no one-size-fits-all answer to all these questions.

Different tasks require different capacities to complete. There is a distinction between driving a car and voting in an election. While an individual may be capable of voting, driving a car safely is a much more complex task. We must evaluate the consequences of reduced capacity in these two tasks to ensure the best outcome for individuals without harming third parties.

Neurodegenerative diseases, such as dementia, present challenges for early diagnosis*(67)*. Families may confuse initial symptoms with typical signs of aging, leading to increased patient monitoring without a proper diagnosis. Unfortunately, this delay can cause individuals living with dementia to lose their independence and autonomy before receiving the necessary assessment and treatment, making it challenging to address ethical issues*(67-70)*.

As dementia progresses, an individual's ability to make decisions will decline, especially in the advanced stages. However, it can be challenging to determine if the disease has affected decision-making capacity during the early stages, which may occur before an official diagnosis. This ethical dilemma raises the question: Can the patient still provide informed consent or advanced directives?

To address concerns about capacity, competence and autonomy in dementia, three clinical interventions can be implemented. First, an early and comprehensive neurocognitive and psychiatric assessment of the patient must be conducted. Second, ensure effective communication and collaboration among patients, families and healthcare professionals. Healthcare professionals should provide information and support to patients and their families regarding clinical and ethical issues. Finally, encourage patients, families and healthcare professionals to collaborate in establishing an early advance care plan*(70-73)*.

Nowadays, there are an increasing number of adequate instruments available to assess the healthcare decision-making capacity of older people*(74-76)*. They can evaluate their capacity to make healthcare decisions, participate in research and engage in everyday decision-making.

Combining neuropsychological assessments and imaging exams with the analysis of dementia biomarkers can enhance the evaluation of a patient's cognitive functions and autonomy*(76-78)*. The autonomy assessment should be comprehensive, incorporating neurocognitive, neuropsychiatric, clinical, and physical evaluations*(74-79)*. This approach ensures that they receive the appropriate care and assistance through an accurate evaluation of their capacity and competence.

After a thorough assessment, it is possible to implement an intervention focused on reducing disabilities and improving autonomy*(22,35,79,80)*. Incapacities not directly connected with dementia, such as hearing loss and visual deficits can be addressed through appropriate interventions*(81-84)*. This can lead to improved cognitive assessment and accurate staging of dementia*(83)*. Furthermore, pharmacological or non-pharmacological interventions designed to treat or mitigate the behavioral and psychological symptoms of dementia have the potential to significantly enhance patient autonomy*(85)*. Continuous assessment is essential to monitor patient progress and adapt care throughout the progression of the disease*(84)*.

Artificial intelligence (AI) and machine learning (ML) can play a crucial role in this intervention. They can provide cognitive training for dementia patients, as well as training apps for caregivers and family members of dementia patients to assist them in providing care*(34,35,57)*. Additionally, socially interactive robots can facilitate daily engagement for those in the early stages of dementia*(57,66,81)*. In the following years, it is expected that a multitude of digital devices will further enhance the care of dementia patients.

The interaction between healthcare professionals, dementia patients and their families and caregivers is fundamental. During the progression of dementia, patient care becomes increasingly difficult, expensive and burdensome for families and caregivers. Insufficient information about the clinical situation, treatments and their consequences hasten the progression of the disease. Discussing ethical issues with families and caregivers is important to inform and support them.

While the interventions mentioned above can help support autonomy, the most effective approach to preserving patients' decision-making abilities—and a degree of their autonomy—is to encourage advance care planning (ACP) as soon as a diagnosis of dementia is established and while patients are competent*(72)*.

ACP is a process that typically involves several voluntary discussions between an individual and any healthcare professional who is familiar with them. Aspects of ACP may include*(86)*: a) discussing the individual's understanding of their illness or prognosis; b) exploring the options available to them; c) identifying their wishes, preferences, priorities and concerns; d) refusing specific treatment if they wish to; e) advocating for someone who is unable to speak for themselves; f) appointing someone to make healthcare decisions for them using a Lasting Power of Attorney; and g) helping individuals communicate their preferences for future care. ACP after a dementia diagnosis must be based on patients' desires, values and technical care issues*(71)*. It includes financial decisions, appointing a durable power of attorney, creating a will, making treatment and clinical intervention decisions, and, when not prohibited by law, deciding on suicide assistance*(71)*.

ACP can help address the bioethical concerns that arise when using AI and ML to care for individuals with dementia. This approach can identify the preferences and limitations of these individuals regarding their future care. However, in this case, besides ACP, it is crucial to establish laws and bioethical guidelines to regulate the use and the limits of these new technologies and approaches.

The first European countries to implement ACP were the United Kingdom (UK), the Netherlands, Belgium, and Germany. In the UK, this implementation was gradually designed, starting in the 1980s. Its main directive was The Mental Capacity Act of 2005*(87,88)*. Currently, 15 of the 28 European Union countries have established specific rules on advance directives, making them legally binding in 86% of cases if they are in writing. Only seven countries require a formal advance directive to be signed before a notary, civil officer or witness. Additionally, the designation of a patient's attorney for health matters is regulated in 11 countries*(89)*.

In Portugal, Law No. 25/2012 contributes to the implementation of appropriate advance care planning. The law regulates ACP, allowing everyone to anticipate making decisions about the end of life and appointing a healthcare proxy. It is registered in the Portuguese National Health System, where the doctors responsible for the patient's care can access their preferences regarding medical treatments and end-of-life interventions.

One of the worst consequences of dementia is the burden it places on families and caregivers. Advanced directives allow patients to make decisions about their future. Establishing advanced directives is the best way to reduce the burden on patients, families and caregivers regarding future complex and sensitive decisions. This practice makes healthcare more efficient and improves the quality of life for families and caregivers.

Although ACP focuses on individuals' well-being, families, caregivers and healthcare professionals involved in the patients' care are the most indirect beneficiaries.

In the absence of advance directive planning, healthcare professionals involved in dementia care must balance between two ethical principles: autonomy and protection. Therefore, if the patient's protection against harmful situations is deemed more important in certain decisions, autonomy must be disregarded. This equilibrated duality is essential for preserving the patients' well-being as the disease progresses.

*Limitations of these solutions for improving dementia autonomy issue*s

Although the solutions for simplifying the ethical issues related to dementia are not complex, there are some challenges in achieving these solutions.

The first challenge is the difficulty of accessing early cognitive evaluation. With the increase in life expectancy and the growing population of older people, many countries are facing an overload of public health services, which makes it impossible to evaluate patients early.

Another limitation is the difficulty families face in accepting or recognising the cognitive problems associated with their parents' or dementia denial and stigma. Today, there is a stigma surrounding a diagnosis of dementia, leading to the denial of the condition*(90)*.

In Portugal, studies have shown reduced access to public health services and a strong dementia stigma in the population which hinders early dementia intervention*(91,92)*. Other European countries, such as Austria, Belgium, Bulgaria, Germany, Greece, Ireland, the Netherlands, Romania and the UK, also encounter challenges in healthcare provision for individuals with dementia, especially in terms of healthcare access and information for patients and their families*(93)*.

The prevalence of social inequalities among older persons poses a significant challenge in accessing vital information and solutions pertaining to ethical dilemmas in dementia. As a result, we must work towards creating a more equitable and accessible system that ensures everyone has an equal opportunity to access the resources they need to make informed decisions.

All these challenges in developing and implementing dementia healthcare information and solutions stem mainly from the increasing aging population, the high cost of dementia care, and the lack of priority in healthcare policy for older individuals.

Conclusions

Despite the different views on autonomy, capacity, competence and the ampleness of ethical issues in dementia care, the topic holds practical importance as it pertains to the daily lives of patients with the disease as well as their families and caregivers. The subject must transition from the philosophical and theoretical domain to medical practice to provide comprehensive care for dementia patients.

Healthcare professionals must be prepared and trained not only for clinical issues but also for ethical and legal considerations concerning all individuals involved in the care of dementia patients. They must understand the dimensions of autonomy, capacity and competence.

Additionally, it is essential that information regarding autonomy, capacity and competence be transparent and readily available to older individuals, caregivers and families. Similarly, information about IC, ACP and other critical directives must also be easily accessible.

Advance Care Planning is crucial for alleviating the stress and burden on caregivers and the families of dementia patients, especially about ethical concerns. It should be readily available to all stakeholders, and public health systems can play a key role in enhancing ACP awareness for patients, families, and caregivers.

Public health policies targeting older people should prioritise improving access to information on ethical dilemmas related to dementia. Moreover, these policies should include ethical guidelines that address novel situations, such as AI and ML. They should also aim to combat the stigma associated with dementia, which often leads to a late diagnosis.

Society and public healthcare policies should collaborate to create a more fair and accessible system that provides everyone with equal opportunities to access the resources necessary to enhance individuals' autonomy and quality of life in dementia, support informed decisions advance care planning, and reduce dementia ethical dilemmas.

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DESARROLLO DE LA COMPETENCIA COMUNICATIVA INTERCULTURAL. DESAFÍOS Y APORTES PARA LA FORMACIÓN DE PROFESIONALES DE LA SALUD

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Resumen: Este trabajo reflexiona acerca de la competencia comunicativa intercultural como aporte para la formación de profesionales en ciencias de la salud. Se visualiza un modelo de salud reduccionista, tecnocrático y descontextualizado culturalmente, y se aprecia como gran barrera el escaso desarrollo de la "competencia comunicativa intercultural" en profesionales de la salud, lo cual dificulta la comunicación con pacientes de otras culturas. Por tanto, es de vital relevancia desarrollar esta competencia en la formación de estos profesionales. Ello implicará, desarrollar componentes que subyacen a esta competencia, esto es, conciencia intercultural, sensibilidad intercultural y eficacia intercultural, lo que permitirá la adquisición de habilidades cognitivas, afectivas y conductuales que beneficien una comunicación efectiva y apropiada con los pacientes de contextos culturales y sociales diversos. Asimismo, les permitirán comprender en profundidad aspectos, valores y prácticas que subyacen a un sistema de salud culturalmente distinto, y promoverá el avance en el conocimiento, compresión y desarrollo de prácticas innovadoras y pertinentes en el sistema de salud, desde un enfoque intercultural e integral. Finalmente, permitirá superar en parte las desigualdades, incomprensiones, prejuicios, exclusiones e injusticias sociales.

Palabras clave: salud intercultural, educación intercultural, competencia comunicativa intercultural.

Development of intercultural communicative competence. Challenges and contributions for the training of health professionals

Abstract: This paper reflects on intercultural communicative competence as a contribution to the training of professionals in health sciences. A reductionist, technocratic and culturally decontextualized health model is visualized, and the scarce development of "intercultural communicative competence" in health professionals is seen as a great barrier, which hinders communication with patients from other cultures. Therefore, it is vitally important to develop this competence in the training of these professionals. This will imply developing components that underlie this competence, that is, awareness, sensitivity and intercultural efficacy, which will allow the acquisition of cognitive, affective and behavioral skills that benefit effective and appropriate communication with patients from diverse cultural and social contexts. Likewise, they will allow them to understand in depth aspects, values and practices that underlie a culturally different health system, and will promote the advancement in the knowledge, understanding and development of innovative and relevant practices in the health system, from an intercultural and comprehensive approach. Finally, it will make it possible to overcome inequalities, misunderstandings, prejudices, exclusions and social injustices.

Keywords: intercultural health, intercultural education, intercultural communicative competence

Desenvolvimento da competência comunicativa intercultural. Desafios e contribuições para a formação de profissionais de saúde

Resumo: Este artigo reflete sobre a competência comunicativa intercultural como contribuição para a formação de profissionais em ciências da saúde. Visualiza-se um modelo de saúde reducionista, tecnocrático e culturalmente descontextualizado, e o escasso desenvolvimento da "competência comunicativa intercultural" nos profissionais de saúde é visto como uma grande barreira, que dificulta a comunicação com pacientes de outras culturas. Portanto, é de vital importância desenvolver essa competência na formação desses profissionais. Isso implicará desenvolver componentes que fundamentam essa competência, ou seja, consciência, sensibilidade e eficácia intercultural, o que permitirá a aquisição de habilidades cognitivas, afetivas e comportamentais que beneficiem a comunicação eficaz e adequada com pacientes de diversos contextos culturais e sociais. Da mesma forma, permitirão compreender em profundidade aspectos, valores e práticas que fundamentam um sistema de saúde culturalmente diferente, e promoverão o avanço no conhecimento, compreensão e desenvolvimento de práticas inovadoras e relevantes no sistema de saúde, a partir de uma abordagem intercultural e abrangente. Por fim, permitirá superar desigualdades, incompreensões, preconceitos, exclusões e injustiças sociais.

Palavras-chave: saúde intercultural, educação intercultural, competência comunicativa intercultural

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Introducción

En el plano internacional y chileno, los sistemas educativos modernos han tenido una clara inclinación en el desarrollo de un enfoque de educación monocultural, occidental eurocéntrico, que promueve la racionalidad positivista*(1-3)*, la que se caracteriza por reducir y cosificar todo a objeto, aun al ser humano, mediante la explicación causal y la generalización del conocimiento*(4,2)*. La racionalidad positivista promueve y perpetúa la hegemonía del modelo biomédico*(1,5)* lo cual excluye y dificulta otras formas de conocer, pensar, hacer y comprender*(6)* la salud en contextos de diversidad cultural.

Lo anterior genera una gran inquietud en la realidad social chilena, dado que en Chile existe una variedad de pueblos originarios*(7)*, al tiempo que la población inmigrante ha aumentado de manera significativa y permanente*(8,9)*. Ello ha instalado diferentes tensiones*(10)*, que atañen a ámbitos tan relevantes como la salud y la educación. En este aspecto, los grupos de migrantes y pueblos originarios se enfrentan a obstáculos en el acceso a la salud*(11)*. En Chile, el derecho a la salud desde un enfoque intercultural para los pueblos originarios es muy limitado*(12)*, puesto que se visualiza la hegemonía de un modelo biomédico y la falta de espacios para el desarrollo de la medicina ancestral*(13)*. En este aspecto, se reproducen relaciones que subalternan los saberes y prácticas médicas mapuche*(12,5)*.

En el caso de las personas inmigrantes se visualiza discriminación y prejuicios, lo cual deriva una exigua y deprivada atención en salud*(14,12)*. En tal sentido, se evidencia en estas personas vulnerabilidad sanitaria y sociosanitaria*(15)*. Lo anterior afecta la atención en salud desde una perspectiva culturalmente diversa.

Lo expuesto genera preocupación, toda vez que a una persona de una cultura diferente se le vulnera en su estado de salud-enfermedad*(16)*. Por el contrario, las personas requieren de personal de salud capacitado en el conocimiento, entendimiento y comprensión de su salud-enfermedad, desde sus diferencias y características culturales, pues son de vital importancia para su calidad de vida y bienestar*(17,3)*. En correspondencia, el ser humano tiene derecho a gozar del máximo de salud que se pueda lograr, sin distinción de cultura, raza, edad, sexo, condición económica o social, religión, ideología política, entre otras*(18)*.

A pesar de los esfuerzos por brindar salud intercultural a través de políticas, como las leyes 19.937*(19)* y 20.584*(20)*, estas normativas han sido débiles, dado que el modelo de salud de Chile es reduccionista, tecnocrático*(21)* y descontextualizado de la realidad cultural de los grupos minoritarios*(12)*. En este contexto, en el sistema de salud de Chile emerge una gran barrera, asociada a la comunicación entre profesionales de la salud y pacientes provenientes de culturas distintas, dado que la comprensión y entendimiento lingüístico está relegado*(22)*, pues se encuentra en un estado precario*(23)*.

Lo anterior es respaldado por Galdámez y Millaleo*(12)*, quienes visualizan escasez de iniciativas para la superación de barreras idiomáticas, puesto que se encuentran poco abordadas en la formación de los profesionales de la salud. Esto resulta preocupante, dado que problemas en el proceso de comunicación entre profesionales en salud y pacientes pueden ocasionar malentendidos, incomprensiones y ambigüedades*(24)*, así como provocar insatisfacción y diagnósticos errados en la atención*(25)*, entre otras dificultades. Ello obstruye de forma completa el camino hacia lo abierto*(26)*, es decir, obstaculiza el avance hacia una salud culturalmente pertinente. En efecto, genera desigualdades, discriminación e injusticias en la atención en salud*(11,27)* en contextos interculturales.

En atención a lo expuesto, es de vital importancia desarrollar la "competencia comunicativa intercultural" en la formación de los profesionales en ciencias de la salud, puesto que el idioma y la cultura deben ser percibidos como un todo*(28)*. Para ello, es necesario abordar y desarrollar en los currículos de las carreras profesionales en salud los componentes subyacentes a la competencia comunicativa intercultural, tales como conciencia intercultural, sensibilidad intercultural y efectividad intercultural*(29)*. Ello permitirá desplegar más efectivamente una salud desde una perspectiva inclusiva y holística*(3,27)*, sobre la base de procesos éticos y bioéticos para dar respuesta a los diversos contextos culturales en que se desempeñan los profesionales de la salud.

A partir de los antecedentes y problemas expuestos, este ensayo tiene por objetivo reflexionar en torno a la competencia comunicativa intercultural como aporte para la formación de profesionales en ciencias de la salud.

Competencia comunicativa intercultural

La competencia comunicativa intercultural, es la capacidad de los sujetos para interactuar desde su idioma materno con las personas provenientes de otras culturas*(30)* de manera apropiada y efectiva*(31)*. Incluye las habilidades que utilizan los individuos desde un origen cultural diferente para contribuir a la comunicación de manera eficaz, a partir de comportamientos apropiados y efectivos en determinados contextos culturales y sociales*(32)*. Además, la competencia comunicativa intercultural se conforma por el conjunto de habilidades cognitivas, comportamentales y afectivas, para manifestar conductas adecuadas y efectivas en un contexto social y cultural determinado que beneficien una comunicación suficientemente eficaz*(33)*.

Según lo expuesto, la competencia comunicativa intercultural permite que las personas de distintos orígenes culturales participen en actividades colaborativas y productivas sobre la base de diálogos interculturales*(34)*. De este modo, se genera autoconciencia, adaptación, humildad, construcción de vínculos y capacidad de escuchar (participar en un auténtico diálogo intercultural) para actuar apropiadamente en contextos culturalmente diversos*(35,36)*. El desarrollo de la competencia comunicativa intercultural también fortalece las relaciones sociales basadas en proyectos comunes, orientados a aportar equidad social y bienestar (37), y, por tanto, a brindar una salud de calidad a una sociedad con diversidad cultural.

Componentes que subyacen a la competencia comunicativa intercultural

La competencia comunicativa intercultural se fundamenta en tres componentes claves para su desarrollo: conciencia intercultural, sensibilidad intercultural y efectividad intercultural. Estos tres componentes están estrechamente relacionados (38).

Conciencia intercultural

La conciencia intercultural es el aspecto cognitivo de la competencia comunicativa intercultural y alude a la comprensión de las convenciones culturales que afectan la forma en que pensamos y nos comportamos*(39)*. Al respecto, Van Hooft, Korzilius y Planken*(40)* señalan que es la capacidad de una persona para situarse en el lugar de otra persona, para comprender las visiones de mundo, ya sea de su propia cultura o de una cultura diferente. Desde esta perspectiva, la conciencia intercultural implica, por un lado, la capacidad de tomar conciencia de nuestros valores, creencias y percepciones culturales, y, por otro, la de comprender e interpretar los valores, creencias y percepciones de personas de otras culturas que interactúan en el entorno*(41)*.

En este escenario, se refiere al conocimiento, percepción y comprensión de la relación entre el mundo de origen de una persona y el mundo de personas pertenecientes a otras culturas, lo que origina una conciencia intercultural, que se enriquece con la conciencia de culturas más amplias*(42)* desde un plano social, cultural e histórico del sujeto. Lo expuesto, en el campo de la formación de profesionales de la salud, aportaría a la toma de conciencia del profesional respecto de los valores, tradiciones, creencias, formas de percibir y actuar, desde su sistema de salud. Así como también generaría conciencia y la capacidad de interpretar y comprender el concepto de salud-enfermedad del otro, a partir de sus formas de percibir, pensar y hacer, teniendo en cuenta las tradiciones, creencias, valores de su cultura. En este sentido, cabe destacar que la conciencia intercultural es la base de la sensibilidad intercultural*(38)*.

Sensibilidad intercultural

Para Chen y Starosta*(39)*, la sensibilidad intercultural alude al deseo activo de los sujetos de motivarse para apreciar, comprender y aceptar las diferencias entre culturas desde un nivel afectivo. Al respecto, Sanhueza*(43)* sostiene que la sensibilidad intercultural está relacionada con aquellas capacidades de las personas para producir respuestas emocionales positivas y, al mismo tiempo, controlar las emociones que pueden afectar el proceso de comunicación intercultural. En este sentido, es una habilidad que favorece el desarrollo de emociones positivas encaminadas a comprender y valorar las diferencias culturales y, por tanto, suscita un comportamiento apropiado y efectivo en el proceso de la comunicación intercultural*(44)*. Ello permite tolerar y valorar las diferencias entre distintas culturas desde el respeto por diversidad*(45)*, mediante la relación con los conocimientos, habilidades y destrezas que permiten generar una vinculación satisfactoria con personas de diferentes culturas que forman parte de pueblos, naciones y sociedades*(46)*. En complementación, la sensibilidad intercultural queda caracterizada por la capacidad de relacionar elementos de la cultura propia y de los otros; de actuar como mediador entre la cultura propia y las demás culturas; de movilizar estrategias, técnicas y recursos para establecer contacto con personas de otras culturas, y de superar los estereotipos, prejuicios y discriminaciones culturales*(47)*.

En suma, la sensibilidad intercultural contribuye, desde el ámbito afectivo, a desarrollar habilidades y destrezas que favorecen el reconocimiento, comprensión, valoración y legitimación de la alteridad desde la diferencia, posicionándose en el lugar del otro, con la finalidad de acceder a diferentes formas de percibir, sentir y comprender el mundo*(48)*, a través de un proceso comunicativo intercultural, basado en el respeto, diálogo y colaboración mutua entre miembros de diferentes culturas que interactúan y conviven en la misma sociedad*(49)*. Todo ello tiene un impacto positivo en el área de la salud, desde el plano del conocimiento, afectivo y actitudinal, para interpretar y comprender al otro desde la diferencia.

En tal sentido, resulta necesario que los profesionales en formación en ciencias de la salud adquieran herramientas, capacidades, destrezas para desarrollar la sensibilidad intercultural y, de esta manera, interactuar con pacientes de otras culturas de forma apropiada, teniendo en cuenta el aspecto afectivo. En este contexto, cabe indicar que la sensibilidad intercultural conducirá a la efectividad intercultural*(38)*.

Efectividad intercultural

Está vinculada con el aspecto conductual de la competencia comunicativa intercultural*(38)*, puesto que el objetivo de ser sensible a las diferencias culturales es proporcionar una interacción adecuada con otras culturas de manera eficaz*(50)*. Desde esta perspectiva, la efectividad intercultural se entiende como el conjunto de habilidades comunicativas verbales y no verbales que evidencien una adaptación de la conducta a la situación y contexto, para favorecer la comunicación de forma apropiada y efectiva*(51)*. En esta misma línea, Portalla y Chen*(52)* sostienen que la efectividad intercultural corresponde a las habilidades y destrezas comunicativas, que incluyen conductas tanto verbales como no verbales y que favorecen el logro de sus objetivos comunicativos en el proceso de interacción intercultural, a través de un actuar adecuado y eficaz.

La incorporación de la efectividad intercultural en la formación de los profesionales de la salud adquiere especial relevancia, pues implica formarlos para desarrollar destrezas y habilidades comunicativas desde un enfoque intercultural*(53)*. Ello promovería efectividad y equidad en la atención en salud*(54)*, y evitaría ambigüedades e incomprensiones en la comunicación, lo cual facilitaría la comunicación efectiva verbal y no verbal entre el profesional y el paciente de otra cultura*(55)* durante el proceso de atención y cuidado.

Conclusiones

Es posible apreciar que el modelo de salud en Chile opera desde un plano reduccionista, tecnocrático y descontextualizado de la realidad cultural. Además, en este contexto, emerge como una gran barrera para la comunicación entre profesionales de la salud y pacientes provenientes de diversas culturas, debido en gran parte a la ausencia en el desarrollo de la “competencia comunicativa intercultural” por parte de los profesionales de la salud. Ello genera discriminación, desigualdades e injusticias en la atención en salud en contextos interculturales.

En atención a lo anterior, es ineludible incorporar la competencia comunicativa intercultural en la formación de profesionales en ciencias de la salud, tanto en pregrado como en especialidades médicas, con el fin de que puedan interactuar con personas de otras culturas desde su idioma materno. Asimismo, el desarrollo de dicha competencia permitirá la adquisición de habilidades cognitivas, conductuales y afectivas que beneficien una comunicación efectiva en determinados contextos sociales y culturales. Para ello, es necesario desarrollar los componentes que están a la base de la competencia comunicativa intercultural: conciencia intercultural, sensibilidad intercultural y efectividad intercultural, los cuales están estrechamente relacionados.

La conciencia intercultural en la formación de profesionales de la salud permitirá situarse en el lugar del otro desde una perspectiva abierta, para tomar conciencia y comprender más en profundidad el sistema de salud del otro, considerando para ello su cultura: tradiciones, creencias, valores y modos de percibir, hacer, actuar y reflexionar. De modo que la conciencia intercultural es la base para promover la sensibilidad intercultural, la que contribuirá al desarrollo de emociones positivas frente a la interacción entre profesionales de la salud y pacientes de culturas distintas. Además, permitirá al profesional en ciencias de la salud desarrollar habilidades y destrezas para comprender al paciente, y para valorarlo y aceptarlo en su diferencia desde un plano afectivo. Por tanto, evitará las estigmatizaciones, prejuicios y discriminaciones. Para ello, además, se precisa de la comunicación efectiva desde un enfoque intercultural, la cual promoverá la adquisición de habilidades y destrezas comunicativas, verbales y no verbales. Ello evitaría una comunicación monocultural y, por lo tanto, ambigüedades e incomprensiones entre el profesional de la salud y el paciente, así como también impediría diagnósticos y prescripciones de medicamentos errados, e insatisfacción en la atención y cuidado en salud, entre otras. Ello favorecerá la comunicación de forma apropiada y efectiva en una situación y contexto cultural diverso.

El desarrollo de estos componentes, que forman parte de la competencia comunicativa intercultural en la formación de profesionales de la salud, permitirá a estos profesionales, evitar prejuicios, exclusiones, incomprensiones y prácticas médicas descontextualizadas hacia el otro. En tal sentido, aportará en la interacción con personas de otras culturas de manera apropiada y efectiva, para interpretar y comprender en mayor profundidad prácticas, valores y aspectos que subyacen a un sistema de salud de una cultura distinta. Asimismo, favorecerá la interacción entre el profesional de la salud y el paciente que proviene de un contexto cultural diverso, y se enriquecerán las relaciones entre profesionales en ciencias de la salud y personas experimentadas en salud provenientes de culturas distintas.

Se requiere entonces que el Estado genere políticas educativas orientadas a promover un proceso de enseñanza y aprendizaje contextualizado culturalmente en la formación de profesionales en ciencias de la salud. Lo expuesto contribuirá a avanzar en el conocimiento y, por tanto, en la comprensión y desarrollo de prácticas innovadoras y pertinentes en el sistema de salud, considerando para ello el diálogo, la colaboración y la reciprocidad constantes con los miembros pertenecientes a culturas diversas, para superar las desigualdades, exclusiones e injusticias sociales.

Conflicto de intereses

Lo autores no tienen conflictos de interés

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PROMOTING ETHICAL GOVERNANCE: A COLLABORATIVE FRAMEWORK FOR END-OF-LIFE CARE POLICIES FOR THE ELDERLY IN CHINA

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Abstract: Delivering end-of-life care services to elderly patients, addressing their physical and psychological needs, enhancing their quality of life, and preserving their dignity represent not only advances in human civilization, but also crucial benchmarks for a country's social development and justice. Effective provision of end-of-life care services hinges on robust national policies, adequate investment, and a cohesive societal effort. Clearly defining the roles and interplay between the government and society is paramount. This study examines China's end-of-life care policies through an ethical lens, aiming to elucidate the nation's stance on national and societal duties and ethical dynamics in end-of-life care development. The research reveals that, ethically, China's end-of-life care services require enhancements in legislative empowerment, regulatory oversight, financial backing, and the functioning of social entities. The absence of government and societal functions, along with inadequate collaboration and synergy between the two sectors, has led to incomplete fulfillment of the diverse end-of-life needs of the elderly. Consequently, China's end-of-life care sector should strive for a transparent delineation of responsibilities between the government and society, as well as precise ethical positioning.

Keywords: end-of-life care, government, society, ethical relationships, well-being

Promoción de la gobernanza ética: un marco colaborativo para las políticas de cuidados al final de la vida de los ancianos en China

Resumen: La prestación de servicios de cuidados al final de la vida a pacientes de edad avanzada, la atención de sus necesidades físicas y psicológicas, la mejora de su calidad de vida y la preservación de su dignidad representan no sólo avances en la civilización humana, sino también puntos de referencia cruciales para el desarrollo social y la justicia de un país. La prestación eficaz de servicios de cuidados al final de la vida depende de políticas nacionales sólidas, una inversión adecuada y un esfuerzo social cohesivo. Es fundamental definir claramente los roles y la interacción entre el gobierno y la sociedad. Este estudio examina las políticas de cuidados al final de la vida de China desde una perspectiva ética, con el objetivo de dilucidar la postura de la nación sobre los deberes nacionales y sociales y la dinámica ética en el desarrollo de los cuidados al final de la vida. La investigación revela que, éticamente, los servicios de cuidados al final de la vida de China requieren mejoras en el empoderamiento legislativo, la supervisión regulatoria, el respaldo financiero y el funcionamiento de las entidades sociales. La ausencia de funciones gubernamentales y sociales, junto con una colaboración y sinergia inadecuadas entre los dos sectores, ha llevado a un cumplimiento incompleto de las diversas necesidades al final de la vida de los ancianos. En consecuencia, el sector de cuidados al final de la vida de China debe esforzarse por lograr una delimitación transparente de responsabilidades entre el gobierno y la sociedad, así como un posicionamiento ético preciso.

Palabras clave: cuidados al final de la vida, gobierno, sociedad, relaciones éticas, bienestar

Promovendo governança ética: Uma estrutura colaborativa para políticas de cuidados de fim da vida para idosos na China

Resumo: Prestar serviços de cuidados de fim da vida para pacientes idosos, abordando suas necessidades físicas e psicológicas, melhorando sua qualidade de vida e preservando sua dignidade, representa não somente avanços na civilização humana como também parâmetros cruciais para o desenvolvimento social e a justiça de um país. A oferta efetiva de serviços de cuidados de fim de vida depende de políticas nacionais robustas, investimento adequado e um esforço social coeso. Definir claramente os papéis e a interação entre o governo e a sociedade é fundamental. Esse estudo examina as políticas de cuidados de fim da vida da China através de lentes éticas, objetivando elucidar a posição da nação sobre os deveres nacionais e sociais e a dinâmica ética no desenvolvimento de cuidados de fim de vida. A pesquisa revela que, eticamente, os serviços de cuidados de fim de vida da China requerem melhorias no empoderamento legislativo, na supervisão regulatória, no apoio financeiro e na funcionamento de entidades sociais. A ausência de funções governamentais e sociais, juntamente com inadequada colaboração e sinergia entre esse dois setores, levou a uma satisfação incompleta das diversas necessidades de fim de vida de idosos. Consequentemente, o setor de cuidados de fim de vida da China deve esforçar-se por uma delimitação transparente de responsabilidades entre o governo e a sociedade, bem como por um posicionamento ético preciso.

Palavras chave: cuidado de fim de vida, governo, sociedade, relações éticas, bem-estar

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1. Introduction

As the aging population grows and societal risks multiply, a rising number of elderly individuals encounter terminal illnesses like cancer, often contending with isolation and impersonal medical interventions*(1)*. The pursuit of rational and compassionate end-of-life care becomes imperative to preserve their quality of life and dignity, representing a hallmark of human civilization advancement and a pivotal gauge of a nation's social progress, justice, and cohesion.

Currently, China grapples with pressing issues such as an aging population and weakened family structures, particularly concerning the elderly's emphasis on quality end-of-life care, encompassing palliative and end-stage support. Certain developed nations, having advanced into aging societies, have amassed valuable insights into public awareness of end-of-life care, pertinent training, analgesic employment, and transparency in doctor-patient relationships, offering potential lessons for China. Effectively leveraging scarce resources to furnish exceptional and comforting end-of-life care for terminally ill elderly individuals, catering to their end-of-life requirements, safeguarding their rights, enhancing their quality of life, and upholding their dignity in death constitutes a responsibility not only incumbent upon the government, but also society at large. Accordingly, delineating the responsibilities and interplay between the government and society holds paramount importance for the wholesome progression of end-of-life care.

In the evolution of the end-of-life care movement abroad, it predominantly unfolded as a grassroots, incremental process instigated by civil organizations, with gradual and cautious state involvement. Nevertheless, challenges persist in defining government responsibilities, fostering organic social initiatives, and individual governance, resulting in the marginalization and neglect of end-of-life care services. This article endeavors to delve into the delineation of responsibilities and the interplay between the government and society in the advancement of end-of-life care, subsequently aiming to propose recommendations and strategies for the enhancement of end-of-life care in China.

1.1 Definition of key terms

1.1.1. End-of-life and end-of-life patients

From a medical perspective, the end-of-life signifies the culmination of a disease or accidental injury resulting in an irreversible progression toward clinical death*(2)*, Dying represents an inevitable phase preceding the conclusion of human life, constituting a transitional period during which individuals inhabit the space between life and death. This transition embodies a gradual shift from a quantitative state to a qualitative one. End-of-life patients encompass individuals who are approaching the threshold of death but have not yet reached the clinical stage of demise, inclusive of elderly individuals, adults, and those who are not critically ill*(3)*. In the context of this study, end-of-life patients primarily denote elderly individuals who no longer respond to curative treatments for their ailments, experiencing a continued deterioration with a relatively brief remaining survival period.

1.1.2. End-of-life care

End-of-life care, with its origins tracing back to the medieval era in Europe, initially served as a sanctuary where pilgrims, travelers, and soldiers could find respite and rejuvenation. Over time, it evolved into a specialized setting catering to individuals afflicted with incurable diseases on the verge of death*(4)*. The end-of-life care examined in this article pertains to delivering appropriate treatment, medical attention, and comprehensive physical and psychological support to patients with a life expectancy of six months or less, aiming to alleviate their physical discomfort and mental anguish. The objective is not to cure the illness or prolong lifespan, but rather to enhance the patient's quality of life, uphold their dignity, and facilitate a dignified passage in the final stages. The goals of end-of-life care encompass refraining from artificially abbreviating or intentionally extending the patient's life span, prioritizing compassionate care, honoring the patient's rights and dignity, and prioritizing the patient's quality of life.

1.2 Theoretical basis

1.2.1. Social welfare models

In 1958, Harold Wilensky and Charles Lebeaux introduced the influential dichotomy of social welfare, namely the Residual Model and Institutional Model, in their book "Industrial Society and Social Welfare: The Impact of Industrialization on the Supply and Organization of Welfare Services." The Residual Model underscores the role of the family and market, emphasizing their responsibility to furnish the necessary welfare for individuals*(5)*. According to this model, only when the family and market mechanisms falter in providing essential welfare benefits will the state and government assume corresponding responsibilities. Conversely, the Institutional Model highlights the role of the state and government, asserting that the state bears an inherent responsibility for fulfilling individuals' welfare needs. This model advocates the reliance on a comprehensive regulatory system led by the state and government to supply individuals with the requisite social welfare. Similarly, British scholar Richard Titmus proposed a comparable classification standard, contending that the Residual Model is an outcome of market failure, and the state only offers limited social welfare to its citizens*(6)*. He emphasized that the Institutional Model represents a social policy aimed at enhancing the welfare standards of the entire populace. Regardless of the categorization or analytical approach, Western social welfare theory and related discussions can offer a relatively sound analytical framework and research paradigm for the establishment and advancement of end-of-life care services in China.

1.2.2. Welfare pluralism

The theoretical essence of welfare pluralism centers on the idea that the delivery of social welfare and services involves multiple entities, thereby reducing the predominant role of the government and moving away from a singular provider model*(7:55)*. It also denotes a transformation from a landscape dominated by monopolistic organizations to one that is more diverse and competitive*(8: x. i)*. This theory underscores the involvement of non-profit organizations and other third sectors, aiming to regulate the management of these entities and guide them into the sphere of welfare services. By relaxing constraints on private participation in welfare provision, this approach seeks to bridge the divide between government agencies and individual needs*(9)*.

1.2.3. Theory of the relationship between government and society

The founder of modern civil society theory is Hegel. In his book "Elements of the Philosophy of Right" from 1821, he initially established the analytical framework of "state civil society"*(10)*. Building upon Hegel's work, Marx employed the dialectical relationship between the "economic foundation superstructure" to elucidate the progression of human society*(11)*. Furthermore, Tocqueville expounded on the significance of civil society for democratic politics*(12)*. Habermas further expanded on Hegel's civil society concept, positing the theory of the "state civil society public sphere" ternary structure and systematically exploring the primary function of the "public sphere," which is to establish legitimacy*(13)*. Additionally, the theory of the third sector, rooted in modern economics, employs "market failure" and "government failure" to advocate for the rationality of the existence of the third sector or civil society. These theories scrutinize the origins and functions of government, society, and their interrelationships from diverse perspectives*(14)*.

2. Current situation of end-of-life care for elderly people in China

Internationally, the demographic consisting of individuals aged 65 and above designates different stages of aging: the aging society, the aged society, and the superaged society, corresponding to proportions of 7%, 14%, and 20% of the total population, respectively. Currently, China's elderly population is undergoing rapid expansion. According to data released by the National Bureau of Statistics on January 17, 2024, as of the end of 2023, the number of elderly individuals in China had surged to 290 million, constituting 21.1% of the total population. Within this demographic, a significant portion comprises critically ill elderly individuals and patients with advanced end-stage diseases.

In China, there is a noticeable dearth of laws and regulations governing end-of-life care services, resulting in a lack of a unified management system for such services. The current landscape is characterized by fragmented departmental oversight, ambiguous centralized management, and multiple coexisting management structures. This ambiguity is underscored by unclear management and supervision responsibilities, as well as undefined tasks within these domains. Furthermore, the health department lacks a dedicated management organization, leading to an overall absence of centralized management for end-of-life care services, effectively creating a vacuum in this aspect. Consequently, the clarity regarding what and how to manage end-of-life care services remains uncertain, with responsibilities and tasks inadequately defined.

In China, a considerable number of individuals, including healthcare professionals, are not well-versed in the concept and provision of end-of-life care. When confronted with patient deaths, there is a tendency to adopt an attitude of avoidance and taboo surrounding this topic. Furthermore, there is a lack of systematic education on death within the entire educational system. As a result, the broader society lacks adequate awareness and understanding of the significance of end-of-life care.

According to the theory of market failure and government failure, public goods exhibit non-competitive and non-exclusive consumption characteristics, making their provision susceptible to free riding, resulting in market failure*(15)*. This underscores the view that public goods can only be effectively provided by the government. However, the actual provision of public goods by the government is not without limitations. The theory of government failure elucidates the requirement for non-governmental organizations as institutional entities outside the realms of the market and government*(16)*. It also illustrates the complementary relationship between government and non-governmental organizations in the supply of public goods.

In developed countries such as the UK and Germany, the end-of-life care movement has been a bottom-up and spontaneous initiative driven by the public, with the third sector playing a crucial role. However, in China, the third sector's involvement in the provision of end-of-life care services is limited, and its potential role remains underutilized.

Since the 1990s, several comprehensive hospitals in major Chinese cities have undertaken initiatives to establish end-of-life care wards, with some piloting such wards in oncology specialty hospitals. State-owned institutions comprise the majority of these endeavors, while non-profit and non-governmental institutions of a private non-enterprise nature represent a smaller proportion.

Meanwhile, community health service centers in China have generally not established end-of-life care departments and have yet to develop an organizational network for end-of-life care services within the community system. End-of-life care services have not been incorporated into the functions of community health services, resulting in an inability to adequately address the needs of elderly individuals requiring end-of-life care at home. In general, the current state of end-of-life care services struggles to meet the demands of patients in need, and the scale of these services falls significantly short of the theoretical quantity required.

The needs of terminally ill elderly individuals encompass life care, physical care, psychological support, emotional assistance, and spiritual comfort. Considering the diverse physiological, psychological, and mental conditions experienced by different types of end-of-life elderly individuals, it is crucial to address personalized needs and unique requirements. Presently, the provision of end-of-life care services in China predominantly centers on life care, physical support, pain management, and relief. However, there is a relative scarcity of services focused on emotional care, psychological support, spiritual comfort, and other aspects, resulting in low service quality. Consequently, these limitations hinder the effective fulfillment of certain elderly individuals' needs for high-level services, thereby affecting their quality of life and end-of-life experiences.

3. The relationship between the government and society in end-of-life care for elderly people in China

Building upon the reliance of non-profit organizations on the government, three interrelationships emerge through financial support and funding provision, with the third sector delivering services*(17)*.

Completion: The government provides funding while the third sector delivers services.

Supplementary: The third sector is responsible for addressing needs that the government cannot meet independently.

Advocacy: In this capacity, the third sector acts as a representative of public interest, advocating for policy improvements by the government.

Welfare pluralism advocates for the privatization of welfare in response to the broader crisis facing the welfare state, necessitating a reduction in the government's direct provision of social welfare. On one hand, welfare pluralism underscores the idea that welfare services can be delivered by the public sector, for-profit organizations, non-profit organizations, families, and communities. It envisions the government's role evolving into that of a welfare services regulator, purchaser, manager, mediator of resources, and promoter of engagement by other sectors in service provision. On the other hand, it stresses the involvement of non-profit organizations in filling the void created by the government's retreat from the welfare domain, resisting the overexpansion of market forces, achieving the integration of welfare services, enhancing the efficiency of welfare provision, responding promptly to evolving welfare needs, and bolstering democratic participation through non-profit organizations.

In China's context, the historical underdevelopment of civil society represents a tangible and current national reality. The highly centralized political authority and unified economic and social regulations enforced during the planned economy era held logical and historical significance at that time. These measures equipped the new regime with the resources and capabilities needed to achieve national unity and to initiate modernization, particularly in terms of economic advancement. In an era characterized by an all-powerful government, political authority extended into various spheres and levels of society. This led to the disruption of previous social connections, with political power being utilized to reconstruct them. Social organizations with autonomous traditions also experienced disintegration and were assimilated into the system of political power. Consequently, civil organizations experienced rapid decline or vanished altogether, while grassroots autonomous organizations became integral components of the bureaucratic chain within the political system.

Following the reform and opening up, the highly centralized system began to loosen, with the central government not only decentralizing power to local governments but also to society and the market. Civil organizations started to emerge, and grassroots organizations began to move towards autonomy. However, the development of civil society has remained relatively slow and immature. An equal cooperative relationship between the government and society has yet to be established. Furthermore, while grassroots autonomous organizations have been established, there is still suspicion surrounding the public and autonomous nature of the community. Moreover, the number of civil society organizations remains relatively small, and their scope of activities is significantly constrained.

Specifically regarding end-of-life care services, on one hand, the lack and misalignment of government functions, along with inadequate investment and support, have impeded the development of end-of-life care. On the other hand, the weakness of civil society has hindered the cultivation and growth of end-of-life care hospitals and hospices in the private sector, let alone cooperation and participation among the government, market, and society. Consequently, this situation inherently poses significant obstacles to the healthy development of China's end-of-life care service industry.

Certainly, civil society organizations in China are currently working to build momentum for the advancement of end-of-life care. However, China's end-of-life care services lack adequate development across various aspects including legislative empowerment, management and supervision systems, financial investment, conceptual frameworks, and social organizations. The simultaneous absence of government and social functions, coupled with insufficient cooperation and complementary interaction between the two, has resulted in a significant number of elderly individuals having unmet multi-level end-of-life needs. As a result, end-of-life care is predominantly provided by family members, and professional end-of-life care services remain lacking.

4. Conclusion

4.1 The government should lead the development of end-of-life care

Social welfare is considered a public good, or at least a quasi-public good, as it represents a domain where market mechanisms either fail outright or only partially operate. As such, it can only be effectively managed by the government. This characteristic holds significant importance in the construction and development of social welfare systems in China and other countries. The "government-led" approach essentially represents a middle ground between assuming responsibility and refraining from intervention. In this approach, the government adheres to the principle of "taking action" versus "inaction" in the realm of social welfare construction.

Social welfare systems are established by various countries to address inadequate living security resulting from market failures and to enhance people's quality of life, with the government serving as the primary custodian of the system. However, it is important to note that the government should not exert complete dominance in this field, much less wield excessive power. Instead, it should engage in moderate intervention in the sphere of social welfare, aiming to achieve mutual compensation or balance among the government, market, and society.

Considering the development process and trends in social welfare undertakings across different countries, the adjustment of government responsibilities tends to lead to the establishment of a government-led, socialized social welfare system. In this framework, the government does not solely assume all responsibilities for contributions and management. Instead, it serves as a guiding force, mobilizing various entities such as social organizations, communities, and individuals to provide welfare protection. This approach does not entail completely relinquishing the management of social welfare but rather represents an alternative way for the government to fulfill its responsibilities.

In the realm of end-of-life care services, the government's responsibilities should encompass the following points:

- Establishing regulatory frameworks and standards for end-of-life care services.
- Facilitating financial support and investment in end-of-life care facilities and programs.
- Collaborating with social organizations and communities to ensure comprehensive end-of-life care coverage.
- Promoting public awareness and education on the importance of end-of-life care.
- Providing oversight and evaluation of end-of-life care services to maintain quality and accessibility.

Firstly, in terms of legislation and institutional design, the Chinese legislative body should expeditiously enact the Law on End-of-Life Care Services to grant and establish the right to end-of-life care for individuals, including the elderly, at a legal level. Additionally, policies and regulations pertaining to end-of-life care should be drafted and implemented, accompanied by the formulation of comprehensive design and plans for end-of-life care systems. This proactive approach will create a legal framework that ensures the provision of end-of-life care services and promotes the rights of end-of-life patients.

Secondly, regarding financial support, it is essential to establish clear guidelines for the financing of end-of-life care services, encompassing contributions from central and local government departments as well as social insurance. The Chinese government should formalize and clarify its financial obligations for various end-of-life care initiatives, specifying the proportion and institutionalization of governmental financial responsibilities for end-of-life care contributions and compensation within medical insurance and related security projects. This approach will entail outlining the financial responsibilities of both central and local governments for end-of-life care, ensuring alignment between financial resources and administrative authorities. Additionally, social medical insurance programs should enhance compensation provisions for end-of-life care services, thereby enabling elderly individuals in need of such services to receive appropriate economic support. This multi-faceted approach will help address the financial aspects of providing comprehensive end-of-life care services.

Thirdly, in terms of management, it is important to designate the China Health Commission as the competent department for end-of-life care services. All levels of health departments should establish dedicated end-of-life care departments, clearly defining their responsibilities and tasks. Furthermore, improvements to the public finance system and local government performance evaluation system are essential. This includes formulating comprehensive end-of-life care development plans, promoting the implementation of various end-of-life care policies and regulations, and managing the reasonable allocation of relevant resources. These measures will aid in effectively the daily operation of end-of-life care services. By centralizing responsibility within the China Health Commission and establishing clear management at all levels, the management and delivery of end-of-life care can be streamlined and optimized.

Fourthly, it is crucial to implement effective supervision of various policies and regulations related to end-of-life care. This includes oversight to ensure the diligence of staff within relevant end-of-life care departments, as well as monitoring the appropriate utilization and normal operation of financial resources allocated for end-of-life care. Additionally, supervision should extend to verifying the legality of activities conducted by end-of-life care-related institutions and social groups. By rigorously overseeing these aspects, the government can uphold the integrity and quality of end-of-life care services, promoting accountability and compliance with established regulations and standards.

4.2 Actively cultivate civil society

Absolutely, building on the foundation of government leadership, a framework guided by “welfare pluralism” or “cooperationism” can be actively pursued. This involves fostering the development of civil society, promoting the establishment of non-profit and non-governmental organizations, and enhancing participation and cooperation between the market and society. Encouraging the involvement of social intermediary organizations in end-of-life care services and management is also essential.

Furthermore, a diversified approach to investment entities and multiple investment forms should be embraced to harness the collective initiative of the government, market, social organizations, families, and individuals to advance end-of-life care. This entails attracting private capital for investment in the establishment of end-of-life care institutions and private end-of-life care hospitals. Coordinating and collaborating in the development of various end-of-life care institutions through methods such as “private - public assistance” and “public - private” can unlock synergistic potential.

Moreover, the implementation of tax preferential policies to support the construction of end-of-life care service institutions, including end-of-life care hospitals, nursing homes, day care facilities, and community end-of-life care service centers, is crucial. These policies may include incentives related to land and housing use, service facilities, and reduction or exemption of corporate income tax for the establishment of elderly end-of-life care service institutions, as well as relaxation of registration conditions. By incorporating these strategies, a comprehensive and collaborative approach to advancing end-of-life care can be realized.

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THE RELATIONSHIP BETWEEN COMMUNICATION SKILLS OF NURSING STUDENTS AND THEIR ATTITUDES TOWARDS TEAMWORK: A CASE FROM TURKEY

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Abstract: Effective communication and teamwork have a critical role in nursing. This study aims to determine the relationship between nursing students' communication skills and attitudes toward teamwork (n=334). The communication skills (104.82±11.47) and teamwork attitudes (120.41±13.28) scores of the students were found to be at a high level. The total scores of the communication skills scale (p=0.007) and the scores of the communication principles and basic skills (p=0.001), effective listening, and nonverbal communication (p=0.008) sub-dimensions of the students who received training on teamwork were higher than those of the students who did not receive training. The total scores of the teamwork attitudes questionnaire (p=0.024) and the sub-dimension scores of team structure (p=0.020) and situation monitoring (p=0.048) of the students who received training on teamwork were higher than those who did not receive training. It was found that the scores of male students in the mutual support sub-dimension of the teamwork attitudes questionnaire were significantly higher (p=0.026) compared to female students. There was a moderate positive correlation between the scores of communication skills and teamwork attitudes (r= 0.467, p<0.001). Nursing students had high communication skills and attitudes toward teamwork, and the relationship between them was significant.

Keywords: communication skills, teamwork, nursing students, socio-demographic factors

Relación entre las habilidades comunicativas de los estudiantes de enfermería y sus actitudes hacia el trabajo en equipo: Un caso de Turquía

Resumen: La comunicación eficaz y el trabajo en equipo tienen un papel fundamental en enfermería. Este estudio tiene como objetivo determinar la relación entre las habilidades comunicativas de los estudiantes de enfermería y las actitudes hacia el trabajo en equipo (n=334). Se encontró que las puntuaciones de las habilidades comunicativas (104,82±11,47) y las actitudes hacia el trabajo en equipo (120,41±13,28) de los estudiantes estaban en un nivel alto. Las puntuaciones totales de la escala de habilidades comunicativas (p=0,007) y de las subdimensiones de principios y habilidades básicas de comunicación (p=0,001), escucha eficaz y comunicación no verbal (p=0,008) de los estudiantes que recibieron formación sobre trabajo en equipo fueron más altas que las de aquellos que no recibieron formación. Las puntuaciones totales del cuestionario de actitudes de trabajo en equipo (p=0,024) y de las subdimensiones de estructura del equipo (p=0,020) y de control de la situación (p=0,048) de los estudiantes que recibieron formación sobre trabajo en equipo fueron superiores a las de los que no la recibieron. Se encontró que las puntuaciones de los estudiantes varones en la subdimensión de apoyo mutuo del cuestionario de actitudes de trabajo en equipo fueron significativamente superiores (p=0,026) en comparación con las de mujeres. Se encontró una correlación positiva moderada entre las puntuaciones de las habilidades de comunicación y las actitudes de trabajo en equipo (r= 0,467, p<0,001). Los estudiantes de enfermería tenían altas habilidades de comunicación y actitudes hacia el trabajo en equipo, y la relación entre ellas fue significativa.

Palabras clave: habilidades de comunicación, trabajo en equipo, estudiantes de enfermería, factores sociodemográficos

A relação entre habilidades de comunicação de estudantes de enfermagem e suas atitudes em direção ao trabalho em equipe: Um caso da Turquia

Resumo: Comunicação efetiva e trabalho em equipe tem um papel crítico em enfermagem. Esse estudo objetiva determinar a relação entre as habilidades de comunicação de estudantes de enfermagem e atitudes em direção ao trabalho em equipe (n=334). Os escores de habilidades de comunicação (104.82±11.47) e atitudes de equipes de trabalho (120.41±13.28) dos estudantes foram encontrados em um nível alto. Os escores totais da escala de habilidades de comunicação (p=0.007) e os escores de princípios de comunicação e habilidades básicas (p=0.001), escuta efetiva e comunicação não verbal (p=0.008), sub-dimensões dos estudantes que receberam treinamento em trabalho em equipe foram mais altos que aqueles dos estudantes que não receberam treinamento. Os escores totais do questionário de atitudes de equipes de trabalho (p=0.024) e os escores das sub-dimensões de estrutura de equipe (p=0.020) e monitoramento da situação (p=0.048) dos estudantes que receberam treinamento em trabalho em equipe foram mais altos que aqueles dos estudantes que não receberam treinamento. Os escores dos estudantes masculinos na sub-dimensão de apoio mútuo do questionário de atitudes de equipes de trabalho foram significativamente mais altos (p=0.026) comparados com estudantes femininas. Houve uma correlação positiva moderada entre os escores de habilidades de comunicação e atitudes de equipes de trabalho (r= 0.467, p<0.001). Estudantes de enfermagem tinham altas habilidades de comunicação e atitudes em direção ao trabalho em equipe, e a relação entre elas eram significativas.

Palavras chave: habilidades de comunicação, equipes de trabalho, estudantes de enfermagem, fatores sócio-demográficos

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Introduction

Communication is as important as vital needs in health care and is recognized as a fundamental skill of medical practice*(1)*. Effective communication facilitates the establishment of a relationship based on trust and therapeutic cooperation between healthcare professionals and their patients*(2)*. Additionally, good communication skills are necessary for healthcare professionals to establish positive relationships with their patients and improve their quality of life*(3)*. Despite the outstanding efforts of healthcare professionals, the structure and dynamics of health services sometimes involve unacceptable communication problems*(4)*. Therefore, effective communication skills are essential for all interlocutors and dimensions of health services.

Teamwork involves cooperation, coordination, and communication among team members to achieve the desired results*(5)*. The importance of effective teamwork among healthcare professionals is increasing due to the complex structure of health services, the need to respond quickly to changes, high expectations from service outcomes, and rapid developments in care and treatment technologies*(6)*. Although each member's role in health teams is different from the others, they are complementary to each other. Thus, the essence of providing quality health services today is that specialized healthcare professionals act in close cooperation and effective communication with a team approach*(7)*.

Nursing as a health science is a profession that focuses on serving the needs of people as biopsychosocial beings, requiring scientific knowledge as well as interpersonal, intellectual, and technical abilities and skills. The nursing process is performed through dialogue, interpersonal environment, and specific verbal communication skills*(8)*. Communication skills are among the effective strategies for improving the quality of patient care and health services*(3)*. Inadequate teamwork in nursing services negatively affects patient care and unit operations*(9)*. For the execution of reliable care processes and the consistent delivery of high-quality care, effective teamwork is essential*(4)*. It is reported that inadequate communication and teamwork failure in health services may lead to various negativities and threaten patient safety*(10)*.

The knowledge and exhibition of the attitudes and awareness of nursing students, who are the healthcare professional candidates of the future and will share a long period with the patient, regarding communication skills, teamwork and cooperation within the team in line with the contemporary medical understanding, and elimination of the deficiencies, if any, during their education, will be a guide in solving the problems that may arise in this regard in the provision of health care, and prevent the occurrence of problems and ensure that the quality of health care reaches the desired level.

The questions of the research are as follows:

- What are the levels of communication skills and teamwork attitudes of nursing students?
- Are the socio-demographic characteristics of nursing students effective in their communication skills and teamwork attitude levels?
- Is the relationship between communication skills and teamwork attitudes of nursing students statistically significant?

Materials and Methods

Ethical Approval

Ethics committee permission was received for this study (Protocol No: 2022/70). The study was designed in accordance with the principles of the Declaration of Helsinki. Informed consent was obtained from all volunteer participants.

Universe and Sampling

The study was conducted with 2nd, 3rd and 4th year students in the Department of Nursing, Faculty of Health Sciences of a state university in Turkey. The 1st year students were not included in the study because they were not part of a team providing patient care services. Required institutional permission was received for the study. The data of the descriptive study were obtained through a face-to-face questionnaire technique in March-April 2022. A total of 334 volunteer students who filled up the forms and questionnaires were included in the study.

Data Collection Tools

The data were collected through the "Socio-Demographic Data Form", "Communication Skills Scale" and "Teamwork Attitudes Questionnaire". The required permissions from the authors were obtained for the use of the scales.

Socio-Demographic Data Form

It was created by the researchers to obtain descriptive information about the students. This form consists of 6 questions regarding the gender, age, grade, the status of receiving education on teamwork and health communication of the students and their voluntary preference for the nursing department.

Communication Skills Scale

The scale was developed by Owen and Bugay (2014) to measure the communication skills of university students. The scale consists of 25 items and 5 sub-dimensions. The reliability coefficient of the 5-point Likert-type scale is 0.88. The scale consists of 4 sub-dimensions as communication principles and basic skills, self-expression, effective listening and nonverbal communication, and willingness to communicate (11). In this study, the reliability coefficient of the scale was found to be 0.92.

Teamwork Attitudes Questionnaire

Developed by Baker et al. (2008), the scale identifies the attitudes of individuals toward team structure, leadership, situation monitoring, mutual support and communication. The scale consists of 28 items and 5 sub-dimensions. The Turkish validity and reliability of the scale was conducted by Yardımcı et al. (2011) and Cronbach's alpha value was found to be between 0.70-0.89. The scale is a 5-point Likert-type scale with a range of 28 to 140 points*(7,12)*. In this study, Cronbach's alpha value was found to be between 0.73-0.92. Cronbach's alpha value for all items of the scale was 0.93.

Since there was no cut-off point for the evaluation of the scales, the median values of the scores obtained by the students from the scales were accepted as the cut-off point and the scores below the median value of the scale were categorized and interpreted as low and the scores above the median value of the scale as high.

Statistical Analysis

Statistical analyses of the study were conducted with the SPSS 22.0 package program. The results were expressed as mean, standard deviation, number and percentage values. For the normality distribution of the data, skewness and kurtosis values were examined and the Kolmogorov-Smirnov test was applied. Mann Whitney U test, Kruskal Wallis H test and post-hoc Dunn's test were applied for the analysis of the Teamwork Attitudes Questionnaire which did not show normal distribution. As the data of the Communication Skills Scale were normally distributed, independent sample t-test and one-way analysis of variance test were applied. The relationship between the scale scores was calculated through the Spearman correlation coefficient. The relationship level of the correlation coefficient was interpreted according to the criteria as "0,00-0,19: very weak relationship, 020-0,39: weak relationship, 0,40-0,69: moderate relationship, 0,70-0,89: high relationship, 0,90-1,00: very high relationship"*(13)* and p<0,05 was considered statistically significant in the analyses.

Results

Descriptive statistics of nursing students are presented in Table 1. The mean age of the students was 21.34±1.56. Of the students, 76.0% were female and 24.0% were male. Additionally, 33.2% of the students were in the 2nd year, 34.4% in the 3rd year and 32.3% in the 4th year. The proportion of students who received training on teamwork was 54.5%, while the proportion of students who received training on health communication was 76.6%. While 75.1% of the students stated that they voluntarily preferred the nursing profession, 24.9% did not voluntarily prefer the profession (Table 1).

The mean score of the Communication Skills Scale was 104.82±11.47 and the median value was 104.00. The minimum score was 64 and the maximum score was 125 (Table 2). The mean score of the Teamwork Attitudes Questionnaire was 120.41±13.28 and the median value was 120.00. The minimum score was 28 and the maximum score was 140 (Table 3).

No significant difference was found between the groups in the comparison of communication skills scores of nursing students in terms of gender, grade, health communication training and voluntary preference for the department ($p>0.05$). The Communication Skills Scale total scores ($p=0.007$) and the scores of Communication principles and basic skills ($p=0.001$) and Effective listening and nonverbal communication ($p=0.008$) sub-dimensions of the students who received training on Teamwork were found to be higher than those of the students who did not receive training (Table 4).

There was no significant difference between the groups in the comparison of the teamwork attitudes scores of nursing students in terms of health communication training and voluntary preference for the department ($p>0.05$). Male students had significantly higher scores in the mutual support sub-dimension compared to female students ($p=0.026$). While 4th-year students' scores in the mutual support sub-dimension of the scale were significantly higher than the other grades ($p=0.000$), 4th-year students' total scores in the teamwork attitudes questionnaire were significantly higher than 2nd-year students ($p=0.016$). The teamwork attitudes questionnaire total scores ($p=0.024$) and the scores of team structure ($p=0.020$) and situation monitoring ($p=0.048$) sub-dimensions of the students who received training on teamwork were higher than those who did not receive training (Table 5).

A moderate positive correlation ($r= 0.467$, $p<0.001$) was found between the communication skill scores and teamwork attitudes scores of the students. Other correlation values of the scales and their sub-dimensions are presented in Table 6.

Discussion

Nurses are professionals who take responsibility for safe and high-quality care in an increasingly challenging healthcare environment. In today's health services, healthcare professionals with leadership, teamwork and good communication skills are needed*(14).* Effective communication and collaboration among team members allow for better solutions and higher success, while effective communication and teamwork among healthcare professionals have the potential to prevent possible adverse events in service delivery, medical errors and decreases in the quality of care*(15).* In this study, the attitudes of nursing students towards communication skills and teamwork and the relationship between them were revealed.

Nursing services include many tasks such as physical care, emotional support and information exchange with patients, which cannot be performed in the absence of communication*(16).* Effective communication is considered an essential skill for nurses, especially since they spend more time with patients and their relatives than other healthcare professionals*(17).* It is emphasized that nursing students should have strong communication skills in order to cope with the needs and concerns of patients in clinical practice and their professional lives in the future*(18).* The findings of this study revealed that the mean score of communication skills of nursing students was quite high (104.82±11.47). Sancar and Aktaş (2019) found the mean score of communication skills of nursing students to be 91.16±12.99*(19).* On the other hand, Hendekci (2020) found the mean score of nursing students' communication skills to be 99.62±17.31*(20).* It is extremely important to prepare students as individuals with critical thinking and effective communication skills in today's complex health care environment. Health sciences students should have effective communication skills as well as psychomotor skills*(21).* It is stated that effective communication in nursing is not only a personal skill but also a technique acquired during the educational process*(19).* Therefore, good communication skills of nursing students should be recognized as an important part of nursing education and these skills should be supported during the learning process. It is thought that students with high communication

Table 1. Descriptive statistics of nursing students (n=334)

Variables		
Age	21,34±1,56	
	n	%
Gender		
Female	254	76,0
Male	80	24,0
Grade		
2nd year	111	33,2
3rd year	115	34,4
4th year	108	32,3
Status of receiving education on teamwork		
Yes	182	54,5
No	152	45,5
Status of receiving education on health communication		
Yes	256	76,6
No	78	23,4
Voluntary preference for the nursing department		
Yes	251	75,1
No	83	24,9

Table 2. Descriptive statistics of the Communication Skills Scale

	$\bar{x}\pm\sigma$	median	min.	max.	median/min.-max. scores of the scale	Cronbach alpha
Communication Skills Scale	104,82±11,47	104,00	64	125	75 / 25- 125	0,92
Communication principles and basic skills	42,34±4,63	42,00	25	50	30 / 10- 50	0,83
Self-expression	16,66±2,52	17,00	6	20	12 / 4- 20	0,78
Effective listening and nonverbal communication	25,58±3,21	26,00	14	30	18 / 6- 30	0,82
Willingness to communicate	20,23±2,84	20,00	9	25	15 / 5- 25	0,69

($\bar{x}$: mean; σ: standart deviation; min.: minimum value; max.: maximum value)

Table 3. Descriptive statistics of the Teamwork Attitudes Questionnaire

	$\bar{x}\pm\sigma$	median	min.	max.	median/min.-max. scores of the scale	Cronbach alpha
Teamwork Attitudes Questionnaire	120,41±13,28	120,00	28	140	84 / 28- 140	0,93
Team structure	25,82±3,42	26,00	6	30	18 / 6-30	0,81
Leadership	27,41±3,28	29,00	6	30	18 / 6-30	0,92
Situation monitoring	26,86±3,13	27,00	6	30	18 / 6-30	0,86
Mutual support	18,24±4,16	17,00	5	25	15 / 5-25	0,73
Communication	22,08±2,71	22,00	5	25	15 / 5-25	0,86

($\bar{x}$: mean; σ: standart deviation; min.: minimum value; max.: maximum value)

Table 4. The Comparison of Communication Skills Scores of Nursing Students in Terms of Socio-Demographic Characteristics

Variables		**Communication principles and basic skills**		**Self-expression**		**Effective listening and nonverbal communication**		**Willingness to communicate**		**Communication Skills Scale**	
		x̄±(sd)	**p**	x̄±(sd)	**p**	x̄±(sd)	**p**	x̄±(sd)	**p**	x̄±(sd)	**p**
Gender	**Female**	42,24±4,65	,448	16,56±2,57	,172	25,57±3,18	,975	20,13±2,92	,219	104,50±11,51	,358
	Male	42,69±4,59		17,00±2,32		25,59±3,33		20,58±2,59		105,85±11,34	
Grade	**2nd year**	41,82±4,27	,338	16,47±2,53	,604	25,33±3,09	,612	19,85±3,00	,168	103,47±10,75	,315
	3rd year	42,67±4,15		16,77±2,29		25,73±2,77		20,30±2,45		105,46±9,92	
	4th year	42,54±5,41		16,76±2,73		25,67±3,73		20,56±3,05		105,53±13,52	
Status of receiving education on teamwork	**Yes**	43,10±4,49	**,001**	16,85±2,45	,137	26,01±3,11	**,008**	20,39±2,97	,272	106,35±11,28	**,007**
	No	41,43±4,65		16,44±2,59		25,07±3,26		20,05±2,68		102,99±11,45	
Status of receiving education on health communication	**Yes**	42,55±4,61	,137	16,73±2,53	,416	25,74±3,17	,098	20,25±2,82	,813	105,27±11,46	,191
	No	41,65±4,67		16,46±2,48		25,05±3,29		20,17±2,94		103,33±11,42	
Voluntary preference for the nursing department	**Yes**	42,38±4,41	,812	16,63±2,39	,694	25,62±2,99	,729	20,29±2,76	,494	104,93±10,87	,787
	No	42,23±5,28		16,76±2,88		25,46±3,82		20,05±3,09		104,49±13,18	

Table 5. The Comparison of Teamwork Attitudes Scores of Nursing Students in Terms of Socio-Demographic Characteristics

Variables		Team structure		Leadership		Situation monitoring		Mutual support		Communication		Teamwork Attitudes Questionnaire	
		$\bar{x}$±(sd)	p	$\bar{x}$±(sd)	p	$\bar{x}$±(sd)	p	$\bar{x}$±(sd)	p	$\bar{x}$±(sd)	p	$\bar{x}$±(sd)	P
Gender	**Female**	25,90±3,30	,643	27,59±3,00	,220	26,86±3,12	,893	17,92±4,08	**,026**	22,08±2,70	,758	120,35±12,94	,570
	Male	25,55±3,80		26,85±4,01		26,86±3,16		19,25±4,28		22,09±2,73		120,60±14,38	
Grade	**2nd year**	25,67±3,53	,108	27,19±3,56	,192	26,29±3,33	,054	17,74±3,94^{b}	**,000**	21,73±2,85	,106	118,61±14,06^{b}	**0,016**
	3rd year	25,65±2,76		27,87±2,36		27,20±2,81		17,06±3,56^{b}		22,18±2,31		119,97±10,84	
	4th year	26,15±3,92		27,15±3,78		27,08±3,18		20,01±4,42^{a}		22,33±2,93		122,72±14,53^{a}	
Status of receiving education on teamwork	**Yes**	26,13±3,60	**,020**	27,60±3,43	,121	27,10±3,27	**,048**	18,56±4,31	,106	22,18±2,81	,296	121,57±14,09	**,024**
	No	25,45±3,17		27,18±3,10		26,57±2,94		17,86±3,95		21,96±2,58		119,01±12,13	
Status of receiving education on health communication	**Yes**	25,86±10,97	,971	27,55±3,11	,220	27,02±2,99	,107	18,30±4,13	,681	22,17±2,55	,438	120,91±12,52	,434
	No	25,67±14,23		26,94±3,79		26,35±3,51		18,03±4,28		21,78±3,17		118,76±15,48	
Voluntary preference for the nursing department	**Yes**	26,02±3,07	,249	27,61±2,95	,223	27,09±2,78	,085	18,29±4,07	,729	22,30±2,34	,062	121,31±11,50	,180
	No	25,22±4,29		26,80±4,10		26,17±3,95		18,07±4,43		21,42±3,54		117,67±17,39	

Table 6. The Correlation Analysis Between Communication Skills and Teamwork Attitudes Scores of Nursing Students

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**
1- Team structure	**-**										
2- Leadership	,624**	-									
3- Situation monitoring	,637**	,660**	-								
4- Mutual support	,428**	,260**	,417**	-							
5-Communication	,612**	,600**	,664**	,403**	-						
6- Teamwork Attitudes Questionnaire	,834**	,759**	,833**	,669**	,808**	-					
7- Communication principles and basic skills	,334**	,354**	,373**	,266**	,343**	,417**	-				
8- Self-expression	,317**	,267**	,250**	,268**	,295**	,351**	,643**	-			
9- Effective listening and nonverbal communication	,331**	,346**	,391**	,280**	,384**	,437**	,743**	,672**	-		
10- Willingness to communicate	,317**	,317**	,357**	,283**	,318**	,405**	,631**	,689**	,675**	-	
11- Communication Skills Scale	,384**	,375**	,401**	,310**	,385**	**,467****	,893**	,833**	,855**	,839**	-

**p<0.01

skills will increase the quality of health services, patients' satisfaction and trust in the educational and professional process and will contribute to effective care with the participation of the patients.

Teamwork contributes to the reduction of medical errors based on employee commitment and, accordingly, to higher patient satisfaction and better-quality health services. Besides, it not only increases productivity but also reduces burnout among healthcare professionals*(22).* Safe care processes delivered through effective teamwork form the basis for high-quality care*(4).* Effective teamwork in nursing is considered an important element of a healthy working environment*(23).* From the findings of this study, it was determined that the mean score of teamwork attitudes of nursing students was quite high (120.41±13.28). Çelik et al. (2019) found the mean score of teamwork attitudes of nurses to be 112.11±17.86 in their study*(24).* In the study by Önler et al. (2014), the mean score of teamwork attitudes of nursing students was found to be 112.945±16.03*(25).* It is reported that nursing students cannot experience teamwork sufficiently during their clinical education and that the theoretical courses on professional occupational teams, especially in nursing departments, are not adequately followed in clinical education*(26).* There is evidence indicating that some errors arising from nursing services occur due to inadequate teamwork*(27).* Some errors and complications in healthcare are attributed to failures in team performance rather than individual performance*(6).* Additionally, the World Health Organization emphasizes the importance of professional teamwork and recommends educational programs that equip health students with the necessary skills and competencies to actively participate in effective teamwork*(26).* Since teamwork is an indicator of personal, academic and professional success, higher education institutions include this skill in their curricula*(28).* In the context of the results of this study, nursing students' positive teamwork attitudes indicate that they will make a significant contribution to the provision of safer, effective and patient-oriented care in health services. Moreover, this attitude will help the health system to function better by encouraging collaboration between nurses and other healthcare professionals.

Teamwork behaviors, which are formed as a result of the performance of team tasks, include communication, coordination and cooperation actions of team members*(29).* In daily interactions among healthcare professionals, effective communication and timely information sharing require healthcare professionals to collaborate in a critical way*(30).* According to the findings of this study, the mean total score of the communication skills scale and the mean scores of the communication principles and basic skills, effective listening and nonverbal communication sub-dimensions of the scale of nursing students who received training on teamwork were found to be higher compared to students who did not receive training. In a study evaluating the benefit of teamwork skills training, it was revealed that trained team members had a higher level of knowledge of teamwork competencies, and those who received training showed more competence in planning and task coordination, collaborative problem solving and communication*(31).* It was reported that the teamwork workshop affected the communication skills of pharmacy students, and while the team communication sub-dimension scores of the students in the intervention group increased significantly, no significant change was observed in the scores of the students in the control group*(32).* According to the results of this study, it can be said that the training on teamwork strengthens the communication skills of nursing students. In the process of health service delivery, team communication, especially among nurses who provide the most care to patients, is of critical importance. The studies conducted demonstrate that the lack of communication between team members can lead to various risks for patients*(33).* Therefore, it is thought that communication skills strengthened by teamwork training will support nursing students to be more effective and sensitive in patient care and minimize the negativities to be experienced.

Mutual support in teamwork is defined as "*the ability to anticipate and support the needs of team members with accurate information about their responsibilities and workload*"*(34).* It is reported that the items of the mutual support sub-dimension of the scale include concepts such as cooperation, assistance and support that are important for a team*(35)* According to the findings of this research, the distributions of the teamwork attitudes questionnaire and sub-dimension mean scores were examined and it was found that there was a statistically significant difference in the mutual support sub-dimension with gender variable and the mean score of the males was higher than those of females. In contrast to this study, Çavuşoğlu et al. (2020) found a difference in favor of females in the gender variable in the total score and other sub-dimensions of the scale, except for the mutual support sub-dimension*(35)*. It was reported in another study that there was no relationship between the gender of the nurses and their attitudes towards teamwork*(36)*. Therefore, the results of this study suggest that male students have a more positive approach to cooperation and support and tend to cooperate more.

Nursing students work in teams in clinical practices, simulation-supported education planning and in-course learning activities as their grade level increases. During these processes, the students are expected to act in line with teamwork*(37)*. According to the findings of this study, it is understood that as the grade level increases, the mean total score of the teamwork attitudes questionnaire increases and there is a statistically significant difference between the students of the 2nd and 4th years. For the mutual support sub-dimension of the scale, the students of the 4th years had the highest mean score and there was a statistically significant difference between them and the other grades. In contrast to this study, the study of Çavuşoğlu et al. (2020) revealed that there was no statistically significant difference between the grades of nursing students and the total score and sub-dimension total score distributions of the teamwork attitudes questionnaire*(35)*. In another study, there was a statistical difference between students' grade levels and the scores on the teamwork attitudes questionnaire*(37)* It is stated that the grade level of nursing students is an important factor in the implementation of professional behaviors*(38)*. Considering that teamwork is an important part of professionalization in the field of nursing, the increase in positive attitudes towards teamwork according to grade level in the context of the results of this study is very promising. This may be associated with the increase in positive attitudes towards teamwork in parallel with the increase in the grade level of nursing students and the effect of the training received and the experiences gained during this process. Therefore, it can be thought that students in higher grades are more aware and ready to collaborate and participate in teamwork in nursing practice.

Changes in health services and global demand require the adoption of a patient-centered teamwork approach and the parallel development of healthcare professionals. This is possible through the adoption of a broad culture of values and principles, placing the patient at the center of care. This approach promotes effective team building and development, enhancing the ability to deliver superior care to patients*(39)*. Successful teamwork is recognized as a requirement for many aspects of effective health services and team training is reported to be effective in improving teamwork in health services*(40)*. According to the findings of this study, the mean total score of the teamwork attitudes questionnaire and the mean scores of the team structure and situation monitoring sub-dimensions of the scale of nursing students who received training on teamwork were found to be higher compared to students who did not receive training. Similar to the results of this study, Çavuşoğlu et al. (2020) found that the mean scores of team structure and situation monitoring sub-dimensions were higher in favor of those who received teamwork training*(35)*. On the other hand, in the study by Düzgün et al. (2019), it was found that there was no statistically significant difference between the total mean scores of the teamwork attitudes questionnaire and the mean scores of the sub-dimensions of the scale*(41)*. It was reported that the training on teamwork had a positive effect on the attitudes of nursing students towards teamwork*(34)*. In a study on the importance of teamwork training for nursing students, significant results were obtained in terms of the attitudes towards teamwork of anesthesia and operating room nursing students who received teamwork training*(42)*. In connection with the results of this study, the fact that nursing students who received teamwork training had a higher level of attitudes towards teamwork can be explained by the fact that the training on teamwork focuses on this skill theoretically and practically, increases teamwork awareness and encourages team spirit. All these factors contribute to the development of teamwork skills and a better quality of delivery of healthcare.

The delivery of health care is becoming increasingly complex, requiring health professionals to bring together their critical skills, experience and expertise and work together in the care of the patient. A paradigm shift in which an interprofessional and interdisciplinary approach to patient care emerged has brought the importance of communication skills and teamwork to the agenda*(43)*. There is a very close relationship between teamwork and communication skills. It is stated that effective teamwork relies especially on the communication skills of the members, and in cases where these skills are not sufficiently developed beforehand, the focus on teamwork may initially be ineffective*(44)*. Interpersonal skills, especially teamwork and communication, are both fundamental to good health care and play a decisive role in safe and reliable patient care, as they can help prevent medical errors and reduce patient risk*(45,46)*. Additionally, failures in teamwork and communication are considered among the most common causes of negativity in medical events*(47)*. From the findings of this study, it was determined that there was a moderate positive relationship between the mean total score of the communication skills scale and the mean total score of the teamwork attitudes questionnaire. Besides, there was a statistically significant positive relationship between the sub-dimensions of the scales. The positive correlation between communication skills and teamwork indicates that there is an increasing relationship between these two factors. The findings of this study revealed that communication skills and teamwork positively affected each other. In conclusion, the positive correlation between communication skills and teamwork refers to better patient care, safety, satisfaction and collaboration in health care. Therefore, the development of communication skills for health care professionals and the promotion of teamwork are critical for the improvement of the quality of health services.

Conclusion

It is understood that the scores of nursing students' communication skills and teamwork attitudes are at a high level. The communication skills of students who received training on teamwork are higher than those of students who did not receive training. The students who received training on teamwork have more positive attitudes towards teamwork. The scores of mutual support sub-dimension of male students were significantly higher than those of female students. There was a moderate positive correlation between communication skills and teamwork attitudes scores.

Due to the individual, institutional and patient benefits of teamwork and effective communication skills, it is necessary to identify and implement strategies to increase the awareness of students and professionals in the health field and evaluate the results of these initiatives to find evidence-based best practices.

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QUALITY OF LIFE IN INFERTILE PATIENTS IN BRAZIL: RELIGIOUS SPIRITUALITY AS A COPING MECHANISM

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Abstract: Due to social pressure and individual desire to have children, infertility is often accompanied by suffering and decreased quality of life. Among possible coping mechanisms, religion has been suggested to help improve quality of life. The objective of this study was to verify, in a cohort of Brazilian women undergoing infertility treatment, if there is a relationship between religiosity and quality of life. The sample consisted of 104 volunteer Brazilian women who sought infertility treatment. A FertiQoL and a Religiosity questionnaire were administered. Descriptive statistics were computed, and groups were compared using a Chi-square test. Most of the participants in the study stated that religiosity was associated with well-being, and 90% of them concluded that religiosity was an important process during infertility treatment. The study found that religiosity leads to improved adaptive coping capacity. Although it is difficult to demonstrate causality, results strongly suggest that religiosity plays an important role in adjusting the psychological aspects of infertile women.

Keywords: female infertility, fertilization clinics, medicine, quality of life, religion

Calidad de vida en pacientes infértiles en Brasil: la espiritualidad religiosa como mecanismo de afrontamiento

Resumen: Debido a la presión social y al deseo individual de tener hijos, la infertilidad suele ir acompañada de sufrimiento y disminución de la calidad de vida. Entre los posibles mecanismos de afrontamiento se ha sugerido que la religión ayuda a mejorar la calidad de vida. El objetivo de este estudio fue verificar, en una cohorte de mujeres brasileñas sometidas a tratamiento de infertilidad, si existe una relación entre religiosidad y calidad de vida. La muestra estuvo compuesta por 104 mujeres brasileñas voluntarias que buscaron tratamiento de infertilidad. Se administró un cuestionario FertiQoL y un cuestionario de religiosidad. Se calcularon estadísticas descriptivas y se compararon los grupos utilizando una prueba de Chi-cuadrado. La mayoría de los participantes en el estudio afirmaron que la religiosidad se asociaba con el bienestar y el 90% de ellos concluyó era importante durante el tratamiento de la infertilidad. El estudio encontró que la religiosidad conduce a una mejor capacidad de afrontamiento adaptativo. Aunque es difícil demostrar la causalidad, los resultados sugieren firmemente que la religiosidad juega un papel importante en el ajuste de los aspectos psicológicos de las mujeres infértiles.

Palabras clave: infertilidad femenina, clínicas de fertilización, medicina, calidad de vida, religión

Qualidade de vida em pacientes inférteis no Brasil: espiritualidade religiosa como um mecanismo de adaptação

Resumo: Devido à pressão social e ao desejo individual de ter filhos, a infertilidade é frequentemente acompanhada de sofrimento e diminuição da qualidade de vida. Entre os possíveis mecanismos de adaptação, a religião tem sido sugerida para ajudar a melhorar a qualidade de vida. O objetivo desse estudo foi verificar, em uma coorte de brasileiras em tratamento da infertilidade, se há uma relação entre religiosidade e qualidade de vida. A amostra consistiu de 104 brasileiras voluntárias que procuraram tratamento da infertilidade. Foram administrados os questionários FertiQoL e de Religiosidade. Estatísticas descritiva foram computadas e grupos comparados usando teste do chi-quadrado. A maior parte das participantes no estudo afirmaram que a religiosidade estava associada com bem-estar e 90% delas concluíram que a religiosidade era um processo importante durante o tratamento da infertilidade. O estudo encontrou que a religiosidade leva a uma melhor capacidade de enfrentamento adaptativo. Ainda que seja difícil demonstrar causalidade, os resultados sugerem fortemente que a religiosidade joga um papel importante em ajustar os aspectos psicológicos de mulheres inférteis.

Palavras chave: infertilidade feminina, clínicas de fertilização, medicina, qualidade de vida, religião

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Background

Infertility, defined as the failure to conceive after one year of regular sexual intercourse without the use of contraceptive measures*(1)*, is considered a global health issue*(2)*. It is estimated that 15% of couples are infertile, and a 50% increase in cases has been observed over the past two decades*(3)*. For the purpose of the current study, it is highlighted that in Brazil, according to data from the Brazilian Institute of Geography and Statistics (IBGE), approximately 15 to 20% of couples of reproductive age have infertility*(4)*.

The desire to bear children and constitute a family is a constituent of human instinct and, under this premise, infertility has a potentially devastating effect on couples, leading to negative emotional effects and impacting various aspects of conjugal life*(5)*. In some cultures, there is still an increased social burden of infertility that may lead to feelings of guilt, loneliness, and social stress*(6,7)*.

Some authors have observed a relationship between infertility and conjugal dissatisfaction or distress, with negative effects on conjugal life*(8)*. Moreover, although a male factor is as prevalent as a female factor*(9)*, many still consider infertility mostly a female issue, especially in developing countries, or in countries where a maternal role is valued over the women themselves*(8,10)*. As a result, women are clearly even more affected by the difficulty in achieving motherhood, living in emotional stress and having a lower quality of life than men*(11-13)*. A recent study found a prevalence of up to 52% of depression symptoms in infertile women*(14)*.

Moreover, the impact of infertility leads many couples to physical, psychological, social, and spiritual distress, leading to questions regarding their existence*(15,16)*. In order to achieve emotional balance, some couples embark on a spiritual journey, seeking new meaning or purpose in life through understanding negative events*(16,17)*. A Koenig review (2012) pointed an association between spirituality/religiosity with quality of life and mental health, demonstrating a positive association with emotions such as hope, optimism, and purpose or meaning*(18)*. Although there is no consensus on the definitions of religiosity and spirituality, Renetzky (1979) designates the spiritual dimension as: (i) the power within the human being, giving meaning, purpose, and fulfillment to life, suffering, and death; (ii) the individual's will to live; and (iii) the individual's belief and faith in himself, others, and God. In this way, religious practices and spiritual beliefs are involved by similar feelings*(19)* and, the context of this study, sought to analyze how much spirituality in connection with religion and the strengthening of the bond with faith reflects on the quality of life of the participants.

Studies have shown that belief in a divine being or in eternal life may lead to increased resilience; likewise, infertile couples have been shown to seek counseling from religious leaders more often than from psychologists or support groups*(17,20)*. It is also noteworthy that patients who have incorporated prayers in their infertility treatment routines have obtained increased success rates, and that religion is a good coping strategy for patients with traumatic and adverse situations*(21,22)*. The importance of treating the infertile couple in a way that embraces all their needs is already indicated by the European Society of Human Reproduction and Embryology (ESHRE) and it recommends routine psychosocial care to reduce stress and restore patients' well-being and adherence to infertility treatments*(23)*.

Finally, diagnosis of infertility is often difficult, both physically and mentally, and different coping mechanisms are often experienced throughout treatment. We hypothesize that religious belief and practice may be an important part of coping mechanisms in women undergoing infertility treatment in Brazil. Therefore, in this study we set out to assess, in a cohort of Brazilian women undergoing infertility workup and treatment for conjugal infertility, if religion is related to quality of life.

Methods

A cross-sectional study was carried out at the Assisted Reproduction Clinic – Gera Clinic – São Paulo unit. A total of 104 women were included, aged between 18 and 50 years old. Inclusion criteria were age (between 18 and 50 years old) and a diagnosis of conjugal infertility. Institutional review board approval was received from the Itajubá School of Medicine (project number 3.846.249). Resolution 196/96 guidelines from the Brazilian National Health Council were followed.

Data were collected throughout 2020, via a Google Forms questionnaire, sent by email, and included an informed consent where the patient agreed to participate in the study. For data collection, the following questionnaires were applied:

FertiQoL (Fertility Quality of Life): An instrument translated and revised into Portuguese, consisting of twenty-six items, developed, and validated by Boivin et al. (2011)*(24)* that allows evaluation of the quality of life of men and women who experience fertility problems. Administration time was approximately 10 to 15 minutes.

General Questionnaire: Questionnaire developed for this current study by Oppenheimer et al. that consists of twelve items that assess religious aspects and the influence of religiousness on the quality of life of women with fertility problems. The questionnaire administration time was approximately 5 minutes. Patients were asked what religion or belief system they adhered, how often they participated in religious celebrations, and if this helped in coping with infertility, as well as other questions.

Data were analyzed using SPSS 18.0 for Windows®. Descriptive analysis was performed, with presentation of frequencies and percentages in each group, for the studied variables. Groups were compared using a Chi-square test. Statistical significance was set at 5%.

Results

In total, 104 volunteer women responded to the questionnaires. The first 26 questions corresponded to the FertiQoL questionnaire and the last 12 questions corresponded to the general questionnaire. Results are presented below, according to the order of the questions.

Individual perception of quality-of-life questions demonstrated that 89% of patients undergoing infertility treatment view their health as good or very good, and 61% are satisfied with their quality of life. On the other hand, many patients (67%) reported decreased concentration due to thoughts about infertility. In terms of dealing with the problems of infertility, 43% of patients reported they were able to advance their life plans despite fertility problems, but 26% find it moderately difficult and 31% reported difficulty. Also, 37% of patients felt very or completely exhausted. However, 53% of respondents felt they were partially able to deal with their problems of infertility.

Several women (45%) were very satisfied with the support they have received from friends, but 35% admitted they were more or less satisfied and 20% said they were little or not at all satisfied with the support they received from friends. Most (69%) also reported they are satisfied with their sex life, despite infertility and, although there is difficulty in achieving pregnant, 63% of patients report they are affectionate with their partners (and vice versa), and only 7 % report they are rarely or never affectionate.

When asked about their feelings, 61% of women reported they never or rarely are jealous or rancorous due to infertility, but most patients report being anguished: 46% all the time or often, and 35% sometimes. Most (79%) fluctuate between hope and despair rising from infertility, and over half (51%) feel isolated.

Half of the respondents described their infertility issues interfered with their daily obligations. Moreover, 58% of patients declared discomfort in social situations. However, only 20% felt their family never or rarely understood the problems they were facing, 34% responded their family sometimes understands them, and 46% think that family members are often or always able to understand the infertility problems they face. Moreover, 53% of women interviewed stated their dedication to their partner was strengthened due to their infertility.

Patients also responded with feelings of sadness related to infertility: 45% reported they often or always felt sad and depressed, 32% rarely or never and 23%, sometimes. Also, most patients reported feelings of inferiority to child-bearing persons (71%). Finally, 54% of patients described fatigue.

Although 53% of respondents had declared their relationship strengthened due to infertility, 68% indicated a negative impact of infertility on their marital life, and 53% admitted difficulty in communicating with their partner about infertility. Most (76%), however, are satisfied with their relationship. Aside from difficulty in achieving pregnancy, 50% of patients often or always and 21% sometimes feel social pressure to have children and many (69%) patients feel irritation due to infertility; 51% do not feel physical pain.

The general questionnaire indicated that 66% were in their first treatment, 57% sought or had sought alternative treatments, and 84% changed to a healthier lifestyle. It also provided information about the patients' religion/sect or belief. Most patients declared they followed some religion (figure 1), and most (68%) are engaged in its activities. Over half attend a session, at a temple or equivalent, at least once a week.

In total, 62% of women did not change their religious habits due to infertility. It was found that 93% of patients resort to prayers or religious texts, and religiousness is important to the well-being of 95% of respondents. Most (71%) patients read religious texts or pray daily and 88% believe prayer helps them face their difficulty in achieving motherhood. Patients related that prayers bring them hope (47%), calm (18%), comfort (12%), tranquility (10%), or inner peace (10%), and 3% feel praying is important for personal growth.

The results of the analysis of variables that showed a significant difference in the comparison using the chi-square test are presented below. Patients were more satisfied with their quality of life when they had altered their lifestyle ($p<0.05$) (figure 2).

Women more or less satisfied with the support they have been receiving from friends regarding infertility were those who considered religiousness less important than either woman who declared to be satisfied or unsatisfied with the support received from friends. These patients also reported more frequently resorting to prayer or religious reading when compared to women who were mostly or completely unsatisfied with support received from friends.

Patients who reported frequently or always feeling jealous or rancor due to infertility more frequently altered their habit to attend sessions at a temple or equivalent. Patients who never or rarely fluctuated between hope and despair (13.6%) less frequently altered their habit of attending a session at a temple or equivalent. On the other hand, patients who felt isolated more often altered their habit to attend a session at a temple or equivalent, as did patients that related discomfort in social situations.

Patients that reported feeling understood by their families regarding infertility only at times more frequently sought prayer or religious reading, when compared to patients the never or rarely felt understood. Also, patients that reported feelings of sadness or depression often or always more frequently altered their habit of attending sessions at a religious temple or equivalent when compared to women who rarely felt sad (figure 3).

A lower percentage of women declared that infertility negatively impacted their relationships when they participated in any religion, than in those that did not. Patients that reported social pressure to bear children often or frequently were more frequent in their attendance at religious temples or equivalents, and more frequently prayed or read religious texts.

Patients often or always irritated at infertility issues were also more prone to alter their religious habits in terms of frequency of attendance, when compared to women seldom or never irritated. Moreover, patients in a first treatment cycle were less prone to alter that habit. Finally, patients that changed to a healthier lifestyle were less prone to attend sessions at a religious temple or equivalent than patients who did not.

Discussion

Achieving motherhood and fatherhood is a central purpose for couples of many different cultures*(25)* and receiving a diagnosis of infertility goes well beyond physiologic and laboratory issues, leading to a psychological process characterized by changes in habits and religious standards for couples. Women that deal with infertility undergo not only a physical, but also an emotional process,

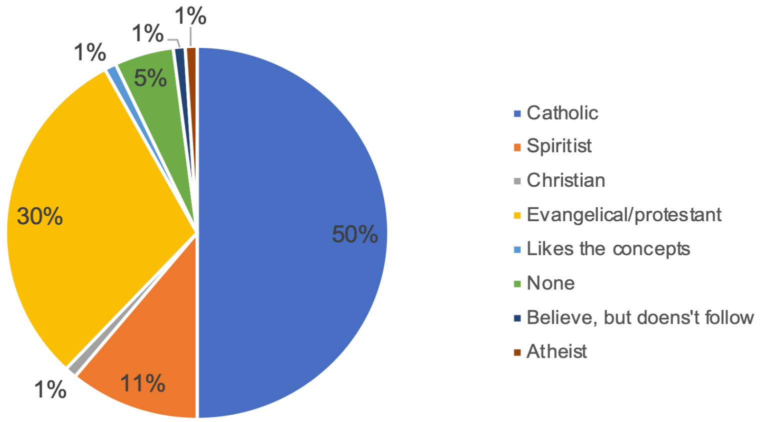

Figure 1. Question 27: what is your religion/belief, if any?

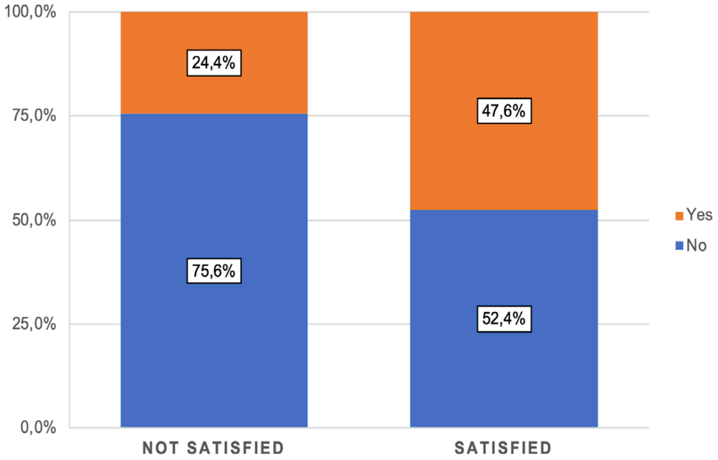

Figure 2. Comparison of change in religious habit in women according to their satisfaction with quality of life.

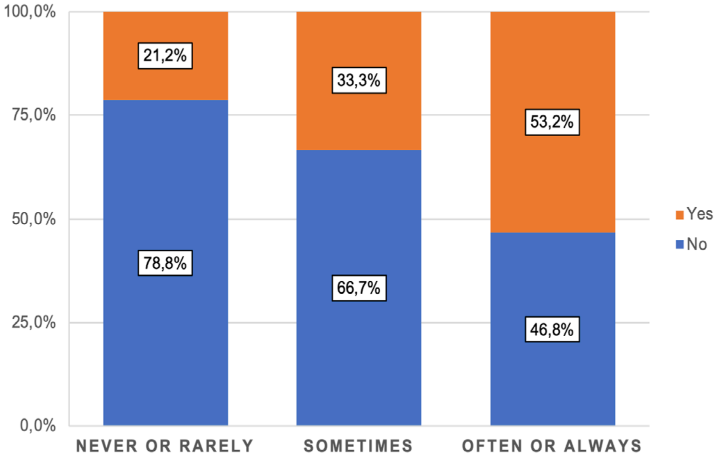

Figure 3. Comparison of change in habit of attending sessions in a temple or equivalent in women according to their frequency of feeling sad or depressed.

before and during infertility treatment*(15,26,27)*. It is understood, then, that infertility treatment also encompasses mental health in many couples; as demonstrated, difficulty or impossibility to achieve pregnancy may lead to feelings of anguish or inferiority in child-bearing people.

This study allowed us to observe the effects of infertility on women in a Brazilian cohort, demonstrating infertility leads to medical situations, as well as social, familial, and religious issues. Moreover, we have demonstrated the manner through which patients cope – both emotionally and socially – with infertility, and their changes in habits following diagnosis of infertility. It is important to emphasize that it was appropriate for the analysis of this study to consider religiosity and spirituality as a single aspect, understanding that spirituality is a personal path in search of meaning to questions about life, and religiosity is related to the individual's belief and religious practice*(18)*. Furthermore, it is also important to clarify that scientific evidence shows the importance of prayer and spirituality in the quality of physical and mental health of patients, as well as in the way they respond to stressful situations*(28)*.

Thoughts of infertility were associated to disturbance in concentration, and many women found it difficult to move on with their life plans; this, in turn, as was demonstrated by Tamannaifar (2011), could lead to feelings of dissatisfaction in life*(29)*. Conversely, results showed that women were resilient to negative feelings and leading with difficulty, because, although many felt exhausted due to infertility, most demonstrated confidence in dealing with the problem.

Many studies have demonstrated reduced self-confidence, increased anguish, depression, stress, and sexual dissatisfaction stemming from infertility, directly affecting the quality of life*(6,7,30)*. In our study, 81% of women admitted to feelings of anguish, and most related they alternated between hope and despair, demonstrating that infertility is associated with emotional distress. A study by Rooney (2018) demonstrates that negative feelings arising from infertility such as shame, guilt and low self-esteem can lead to different degrees of depression and anxiety*(31)*. Also, many women confirmed social crises, stating they feel discomfort in participating in social events, corroborating with authors who state that the majority of infertile women do not share their journey and adversities with friends and family, thus increasing their psychological vulnerability*(31)*. Karaca and Unsal (2012) discuss this, when they state that, in some societies, infertility leads to incapability of living up to social expectations*(32)*.

Moreover, many times, couples in treatment for infertility seek support from religion, leading to improved resilience and quality of life. Importantly, results in our study demonstrated women who were satisfied with their quality of life more frequently altered their habit of attendance at religious temples or equivalents. There is a need to clarify here that, although there is no consensus on the definition of quality of life, according to the WHO, quality of life is an individual's perception of their position in life, in the context of culture and value systems in which that individual lives about his or her goals, standards, concerns, and expectations*(33)*.

In regards to religion, 68.34% of respondents declared to participate in some religious activity, of which 50% were Catholic. Klitzman (2018) stated that a search for religious belief leads to improved outcomes in infertile patients, and that this is expected in situations of internal conflicts in patients*(34)*. In a study in the USA, 51% of respondents were protestant, and 26% were Catholic*(17)*. This occurs because of sociodemographic differences between the USA and Brazil – in the latter, Roman Catholicism is the predominant religion, which explains results in this study*(4)*. In regard to aspects related to religious practice, 93.23% of participants stated they regularly prayed, and two-thirds that they read daily passages from religious texts. Braga et al. (2019) stated that most patients in their study referred to regular prayer and religious reading, as in our study. The authors infer that decreasing the frequency of prayers is negatively associated with a positive outcome, while maintaining prayers improved response to ovarian stimulation*(21)*.

It is important to highlight that the possible support that infertile women seek in religiosity/spirituality is a very personal aspect, difficult to measure, but it is noted that the search is a coping mechanism and a different view of reality. Through the interviews carried out in this study, it is suggested that religion and/or spirituality can convey a sense of comfort and, mainly, of hope, making it possible to believe in the main achievement of life, even if there is difficulty in achieving it.

Religiousness was referred by 95.19% of participants as having a positive impact on patients' well-being, and 9 in 10 respondents identified religious belief as a support mechanism for coping with infertility. These results demonstrate a positive role for religiousness in improving patient well-being during treatment, which agrees with findings from Casu et al. (2018), who stated that spirituality and religiousness may provide a positive resource in dealing with infertility, as a means for improved quality of life in these couples*(35)*. A study with 264 women undergoing infertility treatment identified that the main negative feeling attributed to failure to achieve pregnancy was depression, and that hope was the predominant feeling when they sought medical care*(36)*, as was found in this study.

When we sought to verify patient satisfaction with support from family and friends and with daily prayers, we observed that patients were most satisfied with support from friends in women with daily religious habits. Therefore, frequent religious habits were better prepared to understand their situation and face the sentimental challenges, which is in accordance with Grinstein-Cohen et al. (2017), who identified that patients declared that social difficulty and experience were more painful than treatment itself, and that religiousness improved negative feelings*(37)*. Collins et al. (2018) further demonstrated the importance of religiousness in facing infertility by showing that three in four patients seek religious or spiritual support, while little over half seek medical care*(17)*.

In regard to feelings of sadness and depression stemming from infertility, when related to attendance in religious temples or equivalents, results from our study demonstrated a gradual increase in search for religion in women with negative feelings towards infertility, demonstrating these women seek emotional support in spirituality of religiousness. This is in accordance with Romeiro et al. (2017), who described that the adversity these patients underwent produced spiritual needs in these women as a coping mechanism, incorporating religious teachings as tools to overcome these challenges*(38)*. Likewise, when irritability was correlated to search for the religion, increased attendance was found in women with higher stress levels, similar to the Portuguese study. Tiu et al. (2018) further demonstrated the need for psychological support for patients with increased irritability or stress due to ovulation problems attributed to mood swings*(39)*. The study also suggests that spiritual or religious measures should be employed in order to reduce stress, thus improving results.

Social pressure to bear a child has been related to religious reading habits and to frequency or attendance in religious temples or equivalents, and in both cases, increased social pressures were associated with increased religious habits. Öztürk et al. (2021) agree with the results of this study, demonstrating that social pressure in infertile women is greater than that faced by primiparous fertile women, and that this leads to emotional distress with a need for psychological support, either by specialized psychologists, or by religious practice*(40)*. As a socioeconomic counterpoint to the previous findings, a study from Gambia demonstrated similar results regarding psychological pressure and the search for spiritual support, demonstrating that African populations are prone to seek, frequently, solace in biblical texts or in religious temples*(41)*. Hanselin et al. (2017) stated that infertile patients tend to seek emotional support in religion, but also acknowledge that some religious views may increase psychological pressure in patients*(42)*. Therefore, spirituality and religiousness may play important positive roles in dealing with social pressure faced by patients; however, they suffer the influence of conservative interpretations, which may lead to increased emotional angst.

Limitations

The present study, as it touches on the personal issues of respondents, has some limitations. First, number of participants was lower than initially planned. We also noted the difficulty of the interviewees when the approach had intimate repercussions, such as marital relationships and family life. In addition, there was no characterization of the studied sample regarding the underlying disease, duration of infertility, male or female factor of infertility, age, and other demographic data. Finally, the relationship between attitudes of coping with infertility was not sufficiently clarified, but the positive result of spirituality could be noted.

It is important to highlight the difficulties encountered in the study as a recommendation for future investigations on the same topic.

Conclusion

This study sought to elucidate how patients cope with infertility. It is noteworthy that religiousness leads to improved adaptive capacity, due to the spiritual quest to decrease suffering brought upon by the absence of children, and by improving quality of life. Sadness, depression, irritability, lower quality of life, and social discomfort were greater in patients with no religious belief, as was a decreased perception of support from family and friends.

While the exact relations may not have been adequately demonstrated, results from this study strongly suggest that spirituality plays an important role in adjusting the psychological aspects of infertile patients.

Declarations

Ethics approval and consent to participate.

Institutional review board approval was received from the Itajubá School of Medicine (project number 3.846.249). Resolution 196/96 guidelines from the Brazilian National Health Council were followed.

Consent for publication

Not applicable

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

DO – conception of the study, data collection, results interpretation, drafting of the manuscript. Final approval for submission.

CC – conception of the study, results interpretation. Final approval for submission.

GF – conception of the study, results interpretation. Final approval for submission.

CF – conception of the study, data collection, results interpretation. Final approval for submission.

FR – conception of the study, results interpretation, correction of the manuscript. Final approval for submission.

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PROBING KEY CONCEPTS OF MEDICALLY ASSISTED DEATH. ANALYZING THE PORTUGUESE CONSTITUTIONAL COURT'S RULINGS

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Abstract: From 2021, the Portuguese parliament tried to get four versions of a law on medically assisted death approved. Two were rejected by the Portuguese Constitutional Court (PCC) because they were unconstitutional, and the President politically vetoed another. Finally, the parliament passed the law in 2023, even though the President and the PCC seem to oppose it. In this article, we analyze the PCC's rulings on the medically assisted death law and contend that, broadly speaking, the PCC's decisions to reject the law were justified. We focus on two core questions that have been critical in this debate: the meaning of 'suffering' and of 'permanent injury of extreme gravity'. Further, we point to possible directions whereby the legislators may revise the law and thus solve the problems raised by the PCC.

Keywords: medically assisted death, portuguese constitutional court, unbearable suffering, vagueness and the law, permanent injury

Conceptos clave de la muerte médicamente asistida. Análisis de las sentencias del Tribunal Constitucional portugués

Resumen: Desde 2021, el parlamento portugués ha intentado que se aprueben cuatro versiones de una ley acerca de muerte médicamente asistida. Dos de ellas fueron rechazadas por el Tribunal Constitucional Portugués (TCP), por ser inconstitucionales, y otra fue vetada políticamente por el presidente. Finalmente, el parlamento aprobó la ley en 2023, a pesar de que el presidente y el TCP parecen oponerse a ella. En este artículo analizamos las decisiones del TCP sobre la ley de muerte médicamente asistida y sostenemos que, en términos generales, las decisiones del TCP de rechazar la ley estaban justificadas. Nos centramos en dos cuestiones fundamentales que han sido fundamentales en este debate: el significado de "sufrimiento" y de "lesión permanente de extrema gravedad". Además, señalamos posibles direcciones por las que los legisladores pueden revisar la ley y así resolver los problemas planteados por el TCP.

Palabras clave: muerte médicamente asistida, Tribunal Constitucional Portugués, sufrimiento insoportable, vaguedad y ley, lesión permanente

Uma análise das decisões do Tribunal Constitucional português sobre a morte medicamente assistida

Resumo: Desde 2021, o parlamento português tem tentado aprovar quatro versões da lei da morte assistida. Duas das versões foram rejeitadas pelo Tribunal Constitucional (TC), devido a inconstitucionalidades e o Presidente da República vetou outra versão. O parlamento passou uma lei em 2023, ainda que o presidente e o TC se tenham oposto. Neste artigo, analisamos as decisões do TC sobre esta lei e defendemos que o TC tomou decisões acertadas na maioria das vezes.

Palavras-chave: morte medicamente assistida, Tribunal Constitucional Português, sofrimento insuportável, indefinição e a lei, lesão permanente

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Introduction

Only six European countries have legalized medically assisted death: Luxembourg, the Netherlands, Belgium, Germany, Spain and Austria*(1).* The Portuguese parliament has been trying since 2021 to pass a law to decriminalize medically assisted death but all failed to pass: the Portuguese Constitutional Court (PCC) due to the unconstitutionality of the draft has rejected two, and the President vetoed another for the same reason. Despite these rejections, the law ended up being approved because the problem was the formulation of the law rather than an intrinsic incompatibility between medically assisted death and the Portuguese Constitution. This article provides an ethical analysis of the Portuguese case, which may also be instructive about potential shortcomings in other nations. In particular, our goal is to evaluate the PCC's decision and point toward directions that may help address it. We do this by exploring the meanings of the concepts of 'suffering' and permanent injury of extreme gravity, which were critical for the PCC's rulings against the constitutionality of the draft law. Especially because of the first judgment, we consider that the judges of the PCC were right in their assessment that these concepts were not concrete enough. We, in fact, go beyond the PCC's ruling and add some suggestions for further clarification. This research is different from previous work in at least two ways. Firstly, most research on medically assisted death has focused on the cases of the US, Canada, the Netherlands, and Belgium and, therefore, neglecting the specificities of the Portuguese case*(2-5)*This is particularly significant because of factors such as the context of a Portuguese Catholic culture (rather than a Protestant or laic one), and the use of slightly different concepts from other legislations (such as, in later versions, 'intense suffering' instead of 'unbearable suffering') make the discussion of the Portuguese case quite distinctive. Secondly, this article differs from the few approaches that address the Portuguese context in adopting a more conciliatory aim. On the one hand, those who oppose medically assisted death write about it being difficult to implement in practice*(6)*; on the other, those who support it look at the decision of the PCC with skepticism and dismiss it as a political veto*(7).* This paper, in contrast, accepts the need for the legal regulation of medically assisted death but recognizes the legitimacy of the PCC's concerns and tries to build an approach that makes the law more coherent.

In section 1, we contextualise the status quo in Portuguese law, leading up to the rejection of the law by the PCC and later to the approval of the law by the parliament (without the PCC's approval). In section 2, we discuss the proposed vagueness or indeterminacy of the concepts identified by the PCC, providing examples that indicate how this indeterminacy has been dealt with in other contexts. We suggest some principles and analogies with different cases that can be helpful guidance for redrafting the law. In section 3, we consider objections to our arguments and provide possible responses. We conclude by considering the prospects for a revised law.

As a preliminary point, it is important to mention an explicit limitation of the article: while there are vast expanses of literature on the ethics of medically assisted death generally, it would be beyond our scope to delve deeply into general justifications of, or arguments against, the practice. Instead, we will focus more narrowly on some specific criticisms of a particular proposed law raised by judges in the PCC. Thus our aim is not to reach a firm conclusion about the ethics and legality of medically assisted death but instead to clarify and respond to some particular claims in the context of the Portuguese and the European debate.

1. Medically assisted death in Portugal

Before the entering into force of the law under analysis in this article, medically assisted death was a crime in Portugal. The Criminal Code addressed the issue in three different instances. First, article 134 prohibited the homicide resulting from a request by the victim. Second, article 135 did not allow inciting or assisting suicide. Finally, article 139 forbids suicide propaganda. As a result of the recently approved legislation, these three types of crime do not apply when medically assisted death is executed according to the conditions established in the new Law.

The admissibility of medically assisted death has been debated in legal scholarship, with particular relevance for the field of Constitutional Law, oversimplifying a complex debate, the details of which are not the main objective of this article. We can roughly say that the debate is framed by two opposing views: on the one hand, the fundamental right to life, as established in article 24 of the Constitution, is seen as beyond the power of disposition of its holder; therefore, the individual's autonomy, self-determination or freedom do not constitute legal ground to accept any kind of medically assisted death whatsoever. In this regard, the state must to protect human life which cannot give way in light of any of the mentioned arguments, By contrast, some authors argue that the free development of the personality, as established in article 26 of the Constitution, constitutes a legal ground to accept medically assisted death; in this regard, the argument goes, the individual should be recognized to have general freedom of action and a capacity of self-determination that are broad enough to include the decision to be submitted to medically assisted death*(8–10)*.

From a different perspective, medically assisted death in Portugal has been opposed mostly by Catholic sectors of society and the Portuguese Communist Party*(11)*. While Catholics oppose it for religious reasons, the Portuguese Communist Party has opposed it because medically assisted death would likely negatively impact the worst off and entail providing less quality healthcare to the least economically powerful classes*(12,13)*. Although traditionally, Christian Democrats and Communists held a significant number of parliamentary seats, thus impeding the passing of a law on medically assisted death, this has changed significantly in the last few years*(14,15)*. Indeed, recently, the Portuguese parliament has established a different distribution, including members of the new left and liberals, who are more willing to approve medically assisted death on the grounds of honoring individuals' autonomy. Thus, on 29th January 2021, to decriminalize medically assisted death, the parliament approved a draft law for medically assisted death with 136 votes in favor and 78 against*(11)*.

Version 1

The first version of the proposed law (hereafter version 1) stated that medically assisted death could be allowed if the decision by the patient is informed and a health professional aids the procedure. The *situation must be one of unbearable suffering* and *permanent injury of extreme gravity, with an agreement with what the scientific consensus states* or an incurable and lethal disease when aided by a health professional*(16)*. Maria do Céu Patrão Neves and Cíntia Águas summarise the key features of the draft law very clearly. The draft law allows medically assisted death only 'by decision of the patient, whose will must be current and reiterated, serious, free and informed; in a situation of intolerable suffering, with permanent injury of extreme gravity or incurable, fatal illness, when carried out or assisted by health professionals. Procedural legitimacy limited the applicants to competent adult citizens, of Portuguese nationality or with legal residence in Portugal*(6)*.

The proposed law demanded that a request for medically assisted death covered four steps before gaining approval; firstly, a medical doctor chosen by the patient would approve the request from the patient; then, a specialist doctor would need to corroborate with the first doctor's opinion; following this, a psychiatrist and a clinical psychologist would determine whether the person requesting suicide had made the decision freely; finally, a commission comprising various kinds of professionals (including two health professionals and a specialist in bioethics) would assess the process and approve it if all was found to be in order*(16)*. Hence, the whole process would pass through the evaluation of various professionals to confirm whether the case meets the conditions set in the law.

Although version 1 of the draft law was approved by parliament, making a law in Portugal also requires the promulgation of the President. The President has the choice to promulgate it, veto it, or, in cases where the President is unsure about the proposed law's constitutionality, send it to the PCC to decide whether the law violates the Constitution. In this case, the Portuguese President, Marcelo Rebelo de Sousa, decided to send the proposed medically assisted death law to the PCC for evaluation. In his letter to the PCC, Rebelo de Sousa requested that the constitutionality of two aspects of the law be evaluated. In particular, the President doubted whether the expressions 'situation of unbearable suffering' and 'permanent injury of extreme gravity with an agreement with what the scientific consensus states' are sufficiently specific to protect individuals against haphazard decisions for carrying out medically assisted death*(17)*. The terms, the President contended, were too vague and needed to be more determined so that rights to life and human dignity were not violated. More precisely, according to de Sousa, the law would allow too much personal decision-making power by the health professionals involved in the process of deciding on each specific case. As it stands, the President thought the law did not provide a clear measure of suffering, providing, instead, subjective standards that were open to interpretation by the doctors and commissions evaluating. Moreover, it appears unclear whether the relevant measurement in the law refers to the individuals' suffering or the doctors' assessment of the suffering. According to the President, then, the procedural conditions set out by the law were insufficient to avoid indeterminacy because the terms above were too vague and allowed too much personal opinion from the professionals involved*(17)*.

The PCC's ruling agreed at the core with the President's opinion that the proposed law violated the principle of determinability of law (non-vagueness) and that the law had insufficient normative guidance. The judges disagreed with the President regarding the first point and considered that 'unbearable suffering' can be known "by the rules of the medical profession"*(18)*. Nonetheless, they agreed regarding the second definition concerning the nature of the injury and its determination, which they considered was indeed undeterminable to an extent that rendered it unconstitutional*(18)*. The PCC added, however, that the judges did not consider that medically assisted death is incompatible with the constitution in itself because the right to life is compatible with the autonomous decision to cease one's life. Notably, they contended that the right to life guaranteed by the Portuguese Constitution does not entail the duty to live in every kind of circumstance. Nevertheless, the situations where medically assisted death occurs need to be clear, precise, controlled and anticipable. In short, the problem is not whether medically assisted death is constitutional in itself or violates the right to life, but whether the *means whereby it is practiced* are in keeping with the Constitution*(18)*.

Version 2

After a few months, a second version of the law was sent to the Portuguese president. However, on November 29, 2021, the president immediately vetoed it (without sending it to the PCC) because in his view it had several indeterminacies and a lack of precision. To justify his veto, the president required that the concepts of 'lethal disease', 'incurable disease' and 'serious disease' be further clarified. More precisely, the political veto was taken on two grounds*(19)*. Firstly, the new draft law was self-contradictory: at one point, to be applicable it required a "lethal and incurable disease", while, at other points, it merely required a "serious and incurable disease"*(20)*. Secondly, the President was concerned that widening the scope to include "serious and incurable disease" constituted a significant change in *scope*. The President accordingly asked the parliament to reconsider its deliberation.

Version 3

On 9th December 2022, the Portuguese parliament approved a revised version of the draft law. This draft law responded to the ambiguities noticed by the President, but contrary to the President's opinion, did not circumscribe the scope to cases of "lethal disease". The parliament opted, therefore, for a broader scope. In any event, and despite the mentioned clarifications, the President remained unconvinced about the content of the draft law and asked the PCC to intervene. The President's request for the PCC's inspection was like the previous one, with a concern regarding a violation of the principle of determinability of law. More precisely, although the parliament revised the concepts considered vague before, the President wanted more than the modifications made. Now the parliament defined the disputed concepts as follows:

> 'The concept of 'serious and incurable disease' ought to be understood to refer to a disease that threatens life in an advanced and progressive stage; it is incurable and irreversible, which causes suffering of great intensity (our translation)*(21)*.

> ‘The concept of ‘extremely serious permanent injury’ refers to a serious, permanent and significantly disabling injury that places the person in a situation of dependence on a third party or on the need of technological support to carry out basic activities of their daily life, with a certainty or at least a very high likelihood that such dependency or need will persist over time without the possibility of cure or significant improvement.’ (our translation)*(21).*

> ‘The concept of ‘suffering of great intensity’ means physical, psychological and spiritual suffering, resulting from a serious and incurable illness or permanent injury of extreme gravity, with great intensity, persistent, continuous or permanent and considered intolerable by the subject (our translation)*(21).*

As is clear from the quotes above, contrasting with before, the new draft law submitted did not include the concept of ‘lethal disease’ and only requires that there is an “extremely serious permanent injury” or “serious and incurable illness”. In this new version, there is also a more detailed attempt to clearly define the concepts of “serious and incurable illness”, “extremely serious definitive injury”, and “great suffering”. The proposed new law also sets a minimum period of two months from the beginning of the procedure before medically assisted death is carried out. Finally, it requires the patient to undergo psychological counseling, except if the patient explicitly rejects it. In addition, there is a change from the expression ‘unbearable suffering’ to ‘suffering of great intensity’.

The concerns raised by Rebelo de Sousa were similar to the previous ones that he had sent to the PCC. The President was not sure that changing from ‘lethal illness’ to ‘serious and incurable illnesses was constitutional. Another doubts the President had was whether adding the expression ‘great intensity’ satisfied the constitutional requirements for a proper definition of suffering. Also, he questioned whether the great intensity criterion for suffering referred only to the serious and uncurable illness or also to the permanent injury of serious gravity.

The PCC ruled again that the draft law was unconstitutional, despite disagreeing with most issues that the President raised. Instead, the PCC ruling of the law to be unconstitutional was due to an imprecision regarding categories of suffering in the draft law being “cumulative” or “alternative”. That is, the PCC found it unclear whether someone must suffer physical, psychological and spiritual suffering *together* or whether it is sufficient to suffer *one alone* to be eligible for medically assisted death. The court gave the following clarifying example. If someone suffers from Amyotrophic lateral sclerosis (ALS), but does not experience physical suffering, will this person be eligible for medically assisted death? Consequently, the articles in the draft law that refer to suffering were considered unconstitutional: the ambiguity regarding what kind of suffering is required means that decisions regarding medically-assisted death lack “clarity”, and are not “anticipable” or “controllable”*(21).*

Version 4

The parliament approved a fourth draft of the law on the 31st of March 2023. Pragmatically, it accepted the criticism developed by the Court concerning the definition of “unbearable suffering” and opted for eliminating the reference to the different types of suffering. Indeed, the PCC had already accepted in its first decision that the concept of “unbearable suffering” could be used without violating the Constitution. Nevertheless, the legislator, to densify and improve the determinability of the norm, had adopted the revised notion of “suffering of great intensity.” In this regard, the parliament may have thought, if the three types of suffering – physical, psychological, spiritual – are simply set aside, the remainder of the norm does not result as less determinable than the one previously established in the first draft, which the PCC accepted as constitutional.

Additionally, the determinacy of the norm is maintained by the fact that three conditions must be satisfied for the law to be applied in a particular case: a) the person should suffer from a ‘serious and incurable disease’, or from an ‘extremely serious permanent injury’; b) the person should be in a situation of “suffering of great intensity”; c) a causal link between a) and b) should occur. Given these conditions, it will not be the case that anything goes concerning medically assisted death.

So, for example, someone who simply feels tired of life but has no medical condition would not be eligible for receiving medically assisted death.[4]

However, the Parliament introduced another amendment that proved to be problematic.

Indeed, in this fourth version, and contrary to all previous versions, the modalities of medically assisted death – assisted suicide and euthanasia – appear in a relationship of priority. According to article 3º*(5)*, medically assisted death can only consist in euthanasia when the patient is physically incapacitated to perform medically assisted suicide. That is, if the patient has the physical capacity to self-administering the lethal substance, the patient cannot choose to be euthanised.

This led the President to veto the draft law because it was not clear which doctor should determine the patient's incapacity for that purpose. As explained before, two doctors intervene in this procedure: a medical doctor chosen by the patient and a specialist doctor in the pathology from which the patient suffers. The President noted that nowhere in the draft law was this competence attributed. Furthermore, the President also observed that the draft law did not identify which doctors should supervise the administration of the lethal substances*(22).*

The draft law was, thus, sent back to Parliament without promulgation. In such circumstances, the Parliament has the possibility of confirming the draft law by a super majority of half plus one member of the Parliament (normally, by a supermajority of 116 out of 230 members of Parliament). On the 12th of May 2023, the Parliament confirmed the draft law by a majority of 129 votes. After being confirmed, the draft law should be obligatory promulgated by the President, which occurred on the 16th of May 2023*(23).*

After publication in the Official Journal, the Government should approve a regulation within 90 days, and the law enters into force 30 days after the publication in the Official Journal of the Government's regulation.

2. Vagueness, Suffering, and Grave injury

The Portuguese case raises several issues that are of general ethical interest in other contexts. In this section, we discuss debates surrounding some of the disputed concepts in different versions of the law. In particular, there are significant concerns about what is meant by a) "unbearable suffering" and b) "permanent injury with extreme gravity." In each case, there are issues with the *content* of the term (what is to be determined) and *the process* of determination: who is to make the determination, and what procedure should be followed. In the following sections, we describe these issues, drawing on ethical theory and the experiences of other nations to suggest possible resolutions. In discussing these particular issues, we do not assume these are the only issues of significance. Indeed, there are significant debates about whether these criteria are appropriate in the first place. For instance, it might be questioned why my suffering should become unbearable before I am entitled to assistance in dying. However, the purpose of this article is to provide an ethical critique of the PCC's judgment of the proposed law and point the way for the Portuguese legislator on how to address this judgment, so these broader questions sit outside our current scope.

Vagueness

Before focusing on alleged shortfalls in clarity in the proposed Portuguese law, it is important to say something about the extent to which such clarity is required or desirable. While vagueness is generally undesirable, there are two reasons to resist excessively demanding and constraining legal criteria. First, given that medically assisted death is a topic that reflects the key mores of a society, there must be some room for elected representatives to exert an influence, particularly where reasonable, value-based disagreement about rights exists. For instance, internationally, there is no accepted definition of unbearable suffering*(2).* Hence, the requirement of the PCC cannot reasonably be to offer such a widely accepted definition, which should be supplied about to the mores of a specific society. Taking this on board, where this kind of reasonable disagreement exists, constitutional procedures must provide some leeway allowing elected representatives to legislate*(24).* Here,

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[4] We do not discuss whether this broader scope may be justified in some cases, but see Sumner 2011 and 2022.

the legislator should engage and insist on a wide and inclusive public debate to ensure that she or rightly represents those who elected her or him. Second, in addition to being important from an ethical perspective, concerning the legitimacy of the laws that bind citizens, a degree of flexibility is desirable from a *practical* standpoint since other decision bodies may be better-placed than courts to anticipate and respond to procedural and contextual problems. These responses may be hindered by overly specific prescriptions. With that said, it is important that all parties must be able to know whether they are working within the confines of the law, and we suggest that the PCC's findings point to genuine senses which is unclear in the proposed Portuguese law.

Definition and Typology of Suffering

From the very first version, clauses about suffering raised an initial question about what sorts of pain and suffering should be included in the definition of suffering. In a psychiatric context, Verhofstadt and colleagues identify five different types of suffering: medically related, intrapersonal, interpersonal, societal, and existential*(25)*. Different understandings of what suffering involves raise sensitive ethical questions. Should, for instance, existential pain, such as being 'tired of life' fall within the definition of suffering? Is the dimming of medical pain through palliative care sufficient to reduce the unbearableness of a terminal condition? Should 'spiritual' suffering be included as a distinct category?

A similar lack of clarity accompanies the term 'unbearable.' Such a subjective criterion rests heavily on the evaluations of the person seeking assistance in dying. The proposed Portuguese law allows for several steps of independent evaluation for patients who have requested assistance in dying based on unbearable suffering – including by bioethicists, medical professionals, and psychiatric personnel. This should provide some safeguarding against fleeting evaluations of unbearable suffering. However, the first draft law did not guide the circumstances in which independent authorities may override a person's declared evaluations that their suffering is unbearable. This is important since there is little agreement about what constitutes unbearable suffering from a subjective or objective perspective. For instance, in a qualitative study of patients and practitioners, a participant suggested that having to wear a stoma would constitute unbearable suffering. Another suggested that unbearable suffering is being "alive, but not living." By contrast, a practitioner suggested that unbearable suffering might be a situation in which one must "lie in bed moaning." At the same time, another implied that unbearable suffering may not be somatic at all but associated with "powerlessness"*(26)*. Given the subjectivity of unbearable suffering, there is potential for tremendous conflict between patients' judgements and those of independent evaluators. Under what circumstances, other than lack of capacity, might an assessor legitimately declare a patient's assertion of unbearable suffering to be incorrect or insufficient?

The legislator must give the details of such an answer. In practice, it seems that there would be very few cases where the patient's decision can be undisputedly overruled. Take the example of the Netherlands where various factors, including physical, psychological, social and emotional determinants, have been shown to influence the determination that suffering is unbearable*(27,28)*. Bos and colleagues conclude that:

> Unbearable suffering cannot be measured. It should be regarded as a result of the sum of physical symptoms and existential problems. While the components may not be unbearable, the resulting suffering may be unbearable for the patient*(2)*.

This lack of objective criteria suggests that, provided that the person in question is rationally capable and has repeatedly expressed a desire to die, in practice, there is limited scope for practitioners to overrule a judgement of unbearable suffering. If so, it would be important for Portuguese regulations to clarify and acknowledge this. To the extent that the patient is psychologically competent and not silenced, threatened, inflicted by physical harm, prevented from speaking, or coerced, then there is no reason to overrule her evaluation*(29)*.

The latest draft law version seems not to solve all these problems, albeit it is an improved version of the draft. Significantly, the new draft law gives primacy to the person's subjective perception of their suffering to the extent that it states that the level is to be_determined by *the person who suffers it*. It prolongs the process of evaluation so that there is repeated evidence that there is a clear expression to die, reinforcing the point regarding the subjective nature of the assessment of the person's suffering. Also, by using the concept of 'suffering of great intensity' instead of 'unbearable suffering', the law arguably allows the suffering to be more measurable through physiological criteria*(30-32)*[5] To the extent that it is more measurable, the personal opinion of the professionals involved is more limited, as they are constrained by the data. It rightly adds mandatory psychological counselling and maintains several medical and bioethical specialists in the field to bring a more detailed evaluation. However, despite the changes, it remains somewhat unclear when (and if) the specialists' viewpoint on suffering can overrule the subjective experience of the person suffering and decide that the person's suffering is not very intense.

Additionally, the determinacy of the norm is maintained by the fact that three conditions must be satisfied for the law to be applied in a particular case: a) the person should suffer from a 'serious and incurable disease', or from an 'extremely serious permanent injury'; b) the person should be in a situation of "suffering of great intensity"; c) a causal link between a) and b) should occur. Given these conditions, it will not be the case that anything goes concerning medically assisted death. So, for example, someone who simply feels tired of life but has no medical condition would not be eligible for receiving medically assisted death.[6]

Permanent injury with extreme gravity

Like 'unbearable suffering,' the requirement that there should be a permanent injury with extreme gravity, or analogous clauses, is also widely accepted in other contexts that permit assisted death*(2)*. Unlike unbearable suffering though, permanent injury and extreme gravity appear less susceptible to the charge of subjectivity, since these appear to be primarily a matter of objective medical judgement. Nonetheless, there are some concerns, first, about how the terms 'permanent' and 'extreme gravity' are to be understood.

First, cases of 'permanent' injury will be cases in which potential treatments might eventually be developed or for which better life-prolonging treatments may be found. The PCC expressed a concern that a permanent injury is not identical to an injury from which no recovery is possible. For instance, cancer therapies that aim to extend one's lifespan and alleviate the gravity of various conditions are constantly developing. An injury may be permanent given the existing state of knowledge, but there may still be experimental treatments that could provide a prospect of recovery. Should the presence of such experimental treatments affect judgments of permanence and gravity? This creates some difficulty in determining what counts as permanent and grave injury, which, while not compromising the objective determinability of the law, could become a site of controversy. This provision could be justified under a principle of revisability of the law, according to which those norms that significantly determine a given practice, can be revised and debated after they have been agreed upon. This principle gives leeway for correcting mistakes that may come to light with new evidence*(29)*. Particularly for the case in question, the legal term 'permanent injury' (and, indeed, unbearable suffering) should be scrutinized continuously and repeatedly to ensure that it is up to date in light of new scientific and technological evidence.

Second, the concept of 'consensus' is heavily disputed, as exposed by controversy about the degrees of the scientific consensus around climate change (Doran and Zimmerman 2011). How should consensus about the gravity and permanence of an injury be adequately measured? Does a single prominent dissenting voice undermine a consensus? Should the consensus be reached by Portuguese, European, or international scientists? And what procedures should be in place when there is doubt about whether a consensus exists? Given this lack of clarity about the term, it is important to note that the PCC's broad requirement for clarification is not addressable. Nonetheless, the legislator ought to define *what* is meant by consensus and explain *who* and *why* in terms of

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[5] Although these sources provide slightly more objective standards, this evaluation remains subjective and self-report still remains the primary criterion.

[6] We do not discuss whether this broader scope may be justified in some cases, but see Sumner 2011 and 2022.

the relevant individuals that need to agree on this.

Questions regarding the permanence of an injury and the nature of the consensus required are, again, important to answer, given that the lack of clarity may impede an individual's self-determined choice for assisted death. Again though, it is beyond our scope to attempt a resolution to these difficult issues here. Bos and colleagues note that in a Dutch context, distinct criteria are provided:

> The patient's suffering is considered to be without prospect of improvement if the disease or disorder causing the suffering is incurable, and there is no means of alleviating the symptoms so that the suffering is no longer unbearable… Whether treatments are a realistic option depends on two things: the improvement that can be achieved and the burden such treatment would place on the patient*(2).*

While this does not resolve all the issues above, providing relatively clear criteria for permanent injury with extreme gravity would go some way towards redrafting the law to satisfy the PCC's concern regarding this criterion. The latest draft law is much clearer. It dropped the scientific consensus requirement which was problematic. Additionally, it defines the concept of permanent injury with extreme gravity slightly better because it links it to dependence on daily tasks, which is a clearer and more precise criterion. Although it does not make a direct reference to the development of technology, it is implied that the criterion is dependent on technological advancements that can change this. Even though the PCC has not contested this, we consider that conditions of revisability mentioned above are important to include and these are still lacking in the latest version of the draft law.

3. Practical Difficulties and Dependency

In this section, we wish to address two important objections to this specific law that can be raised in the Portuguese context. One form of criticism is that this policy has difficulties in implementation in Portuguese society*(6).* To start, there seems to exist little interest from civil society on this matter, and health policies should correspond to the will of the people. That is, we have not seen, according to this criticism, the general population of Portugal interested in addressing this issue; it is a minority concern. Neves and Aguas, who raised this criticism, are more concerned about the question of legitimacy. While the democratic legitimacy of the PCC to make legally binding decisions is beyond our scope, there is a practical aspect of this criticism that bears on the practicability of the law. Namely, health policies work better if they have the support of the affected population*(33).* Another practical concern they raise is that there may not be enough trained health professionals who will want to be involved in the process, which would make medically assisted death materially impossible. This concern is especially acute in the Portuguese context because the Portuguese Medical Association is reluctant to support the medically assisted death law*(34).* On top of this, there may be insufficient infrastructure and resources, and consequently, the Portuguese health system will end up offering low-quality service. Neves and Aguas do not argue that this is necessarily the case, but as there are no studies on this, there is a high degree of uncertainty*(6).*

Certainly, the cooperation of the population is critical for the successful implementation of health policies. Nonetheless, this seems more important in cases of infectious diseases where people's behaviour can significantly contribute to the success or failure of the policy*(35).* In the case of medically assisted death, active cooperation seems less pivotal, except when it refers to specific groups within the population, like health professionals. However, it is likely that health professionals (as well as other professionals) will respond to incentives, especially economic ones. It is, therefore, not a fatal problem to have less cooperation of health professionals at the beginning of the implementation of this law and this may indeed change. This leads us to another issue with the objection: it is beyond the scope of the draft law to assure that the required means for implementation will exist in the future. This is rather a matter of policy, which ought not to stop the enactment of a law, and any confusion in this regard would ultimately infringe on the democratic separation of powers. For instance, just because human rights may be difficult to implement, that does not mean that there should be no human rights law as a basis for protecting individuals. Surely, as Immanuel

Kant pointed out, ought implies can*(36)*. But this is not a question of the ability to implement the law but of the number of people who can be aided: this law, even if it cannot reach everyone, can aid some. If this is not sufficient, the critics would have to endorse the levelling-down objection. Derek Parfit argued that the view that it is in itself bad if some people are worse off than others is wrong. To prove this, one prime example he gives is that this theory would imply blinding everyone to make everyone equal. As this is absurd, it cannot be the case that inequality is intrinsically bad*(37)*. The critics of medically assisted death contend that there are not enough resources for everyone and therefore it is better not to have it fall into the same problem. Namely, their argument would imply that it is better to have more people suffering than address some people's suffering just because there are not enough resources for everyone.

The stronger objection relevant in the Portuguese context against the law is that it looks at the concept of dependency acritically. It accepts dependency as a bad thing when there is nothing normatively wrong with it: there is nothing morally wrong with being dependent on another; neither is there anything wrong in providing care to a dependent person. Dependency is a fact of life and comes in degrees. The binary of dependent-independent has a weak foundation on concepts of masculinity which easily disappears when confronted with the facts of life, which demonstrate that everyone is, to a certain degree, dependent on others. There is no indignity in being dependent because it is a normal thing. Nonetheless, there is some indignity in responding to dependency in a negative way, by, for example, perceiving it as inferiority and contending that some dependencies make a life not worth living*(38)*[7]. The Catholic sector of Portuguese society is the one that has raised more or less this concern when they contend that it is normal for people to have relationships of dependency and for some people to take the role of a carer. They contend that relationships of dependency can be a good opportunity to show care and love.

We agree with the underlying theory of this argument that there is nothing intrinsically wrong with dependency – a dependent person is not inferior to others. However, we do not need to deny this to contest the argument. A moral theory can point out what is wrong with a certain idea and, at the same time, recognize that as a matter of law, it needs to be flexible in terms of implementation*(39)*. In the present case, this becomes more evident by looking at the limits of the plasticity of individuals' preferences and values. Although we think that a new perspective on dependency is important, it is also the case that autonomy has gained significant importance in the values of the West, making it core for individuals' self-perception of worth. This tendency needs to be changed, but it is likely unchangeable for people who have been socialized all their lives in this way. Hence, although the reason why they suffer may not be justified by a moral theory, their suffering is very real and possibly irreversible. If the psychological counselling they receive cannot help them look at their condition in a different way, then this ought to be considered an irreversible or nearly irreversible emotional state, which justifies medically assisted death. So if someone cannot stand being dependent, this ought to be respected – independently of our understanding of whether dependency is a good, bad, or indifferent value. Notwithstanding this, society must work towards understanding that dependency is not intrinsically unworthy*(38)*. It is, however, dangerous too probe to much into individuals' personal opinions as it resembles some kind of thought police. It is advisable that any change is carried out indirectly through nudges rather than forcing individuals to change*(40)*.

Conclusion

In this article, we have surveyed ethical aspects of the PCC's judgements that versions of a proposed law decriminalising medically assisted death are unconstitutional. In so doing, we have in many cases agreed with the PCC that there are points at which the proposed law requires clarification, in particular by identifying limitations on health practitioners' capabilities to over-rule subjective suffering. Our paper suggests several ways for the legislator to solve these problems, including problems concerning categories of suffering, which arguably originated at the PCC. In response to this,

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[7] Donaldson and Kymlicka are here referring to the dependency in a different context.

we suggested that removing reference to categories of suffering would improve the determinability of the law. Whilst we have suggested ways to remove some indeterminacy, it is also important to stress that some indeterminacy is inevitable, perhaps desirable, to accommodate resolutions to unforeseen practical problems in implementation. However, vagueness at the outset mustn't threaten fundamental rights to life, dignity, and self-determination. In this respect, there is scope for optimism that the PCC judgement may be a significant step towards an ethically and constitutionally justified assisted death law rather than an implacable obstacle in the path of one.

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SUSTAINABLE ORAL HEALTHCARE FROM ETHICAL STANDPOINT

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Abstract: Sustainability refers to the efficient and balanced use of resources, considering the needs of future generations. Sustainable development and sustainability address the most significant and complex challenges humanity has ever faced. Sustainable healthcare systems consider the long-term social and environmental impacts of health services, utilizing existing resources effectively, and concurrently addressing the health rights of the population. The key components of such systems include reducing, recycling, and reusing medical waste, energy efficiency, minimally invasive practices, and reduced carbon footprint by eco-friendly principles. Oral healthcare, integral to overall well-being, must align with sustainability. Ethical delivery of oral healthcare demands a delicate balance between current patient needs and preserving resources for future generations. Professionals in the field increasingly recognize the imperative to minimize environmental footprints while upholding standards of care. Eco-friendly dentistry emphasizes waste reduction, energy conservation, and the adoption of innovative, sustainable materials and practices. Environmental ethics underscore the interconnectedness of human health and environmental well-being. They advocate for strategies to mitigate environmental health risks and promote sustainable practices in oral healthcare. By embracing sustainability, oral healthcare professionals contribute to a healthier planet and ensure the longevity of their practice for generations to come.

Keywords: dental practice, eco-friendly dentistry, environmental ethics, oral healthcare, sustainability

Atención sanitaria bucal sostenible desde el punto de vista ético

Resumen: La sustentabilidad se refiere al uso eficiente y equilibrado de los recursos, considerando las necesidades de las generaciones futuras. El desarrollo sustentable y la sustentabilidad abordan los desafíos más significativos y complejos que la humanidad haya enfrentado jamás. Los sistemas de atención de salud sustentables consideran los impactos sociales y ambientales a largo plazo de los servicios de salud, utilizando los recursos existentes de manera efectiva y al mismo tiempo abordando los derechos de salud de la población. Los componentes clave de tales sistemas incluyen la reducción, el reciclaje y la reutilización de los desechos médicos, la eficiencia energética, las prácticas mínimamente invasivas y la reducción de la huella de carbono mediante principios ecológicos. La atención de salud bucal, integral para el bienestar general, debe alinearse con los principios de sustentabilidad. La prestación ética de la atención de salud bucal exige un delicado equilibrio entre las necesidades actuales de los pacientes y la preservación de los recursos para las generaciones futuras. Los profesionales en el campo reconocen cada vez más el imperativo de minimizar las huellas ambientales al tiempo que se mantienen los estándares de atención. La odontología ecológica enfatiza la reducción de desechos, la conservación de la energía y la adopción de materiales y prácticas innovadores y sostenibles. La ética ambiental subraya la interconexión de la salud humana y el bienestar ambiental. Aboga por estrategias para mitigar los riesgos para la salud ambiental y promover prácticas sostenibles en la atención de salud bucal. Al adoptar la sostenibilidad, los profesionales de la salud bucal contribuyen a un planeta más saludable y garantizan la longevidad de su práctica para las generaciones futuras.

Palabras clave: práctica dental, odontología ecológica, ética ambiental, salud bucal, sostenibilidad

Cuidados de saúde oral sustentáveis de um ponto de vista ético

Resumo: Sustentabilidade refere-se ao uso eficiente e equilibrado dos recursos, tendo em conta as necessidades das gerações futuras. Os sistemas de cuidados de saúde sustentáveis são aqueles que consideram os impactos sociais e ambientais a longo prazo dos serviços de saúde, utilizando os recursos existentes de forma eficaz e abordando simultaneamente os direitos de saúde da população. Os componentes-chave de tais sistemas incluem a redução, reciclagem e reutilização de resíduos médicos, eficiência energética, práticas minimamente invasivas, redução da pegada de carbono de acordo com os princípios ecológicos. Os cuidados de saúde oral, fundamentais para o bem-estar geral, devem estar alinhados com os princípios de sustentabilidade. A prestação ética de cuidados de saúde oral exige um delicado equilíbrio entre as necessidades atuais dos pacientes e a preservação de recursos para as gerações futuras. Os profissionais do campo reconhecem cada vez mais a imperiosa necessidade de minimizar as pegadas ambientais ao mesmo tempo que mantêm os padrões de cuidado. A odontologia ecológica enfatiza a redução de resíduos, a conservação de energia e a adoção de materiais e práticas inovadoras e sustentáveis. A ética ambiental sublinha a interconexão entre a saúde humana e o bem-estar ambiental. Ao adotar a sustentabilidade, os profissionais de saúde oral contribuem para um planeta mais saudável e garantem a longevidade de sua prática para as gerações futuras.

Palavras-chave: prática odontológica, odontologia ecologicamente correta, ética ambiental, saúde bucal, sustentabilidade

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Introduction

In today's world, many environmental issues have become more severe and pressing than ever before. These include such problems as air pollution, freshwater shortages, deforestation, species extinction, climate change, heatwaves, floods, droughts, forest fires, the spread of infectious diseases, environmental migration, and more. All these problems significantly affect people's health, livelihoods, and overall well-being. Human health is intrinsically linked to the environment and similarly the well-being of the environment is closely related to the sustainability of healthcare services. Such a mutual interaction places a responsibility on healthcare professionals to address diseases caused by adverse environmental conditions on one hand, and simultaneously to make efforts to ensure that healthcare services do not adversely affect the environment, reflecting a bioethical maturity and responsibility*(1-3).* The environmental influences of healthcare practices and the complicated challenge of sustainability give rise to ethical inquiries concerning the environmental stewardship of healthcare. The well-being of the Earth's ecosystems underscores the imperative for healthcare institutions and practitioners to reevaluate their methods, striving to mitigate or eradicate adverse effects. Simultaneously, they must navigate a delicate equilibrium between their environmental responsibilities and their duty to promptly address the pressing needs of patients. Tackling this balance necessitates a thoughtful integration of principles from both medical ethics and environmental ethics*(1).*

Sustainable Development and Sustainability

Sustainable refers to the level at which a resource can be utilized or depleted without compromising its ability to regenerate itself indefinitely*(4).* It was initially introduced in 1980 in the World Conservation Strategy Report, marking the first international document on living resource conservation crafted through collaboration among governments, non-governmental organizations, and various experts. The report advocates that for development to be sustainable, it must actively support conservation rather than impede it. It is tailored for policymakers, conservationists, and development practitioners, emphasizing key principles such as the protection of ecological processes and life-support systems, the preservation of genetic diversity, and the sustainable utilization of species and ecosystems. This influential report played a pivotal role in shaping "Our Common Future", also known as the "Brundtland Report" (1987), laying the groundwork for defining the principle of sustainable development. According to this report, "sustainable development is a development that meets the needs of the present without compromising the ability of future generations to meet their own needs"*(5).*

Based on the information gathered from various sources, it is possible to make the following definition for sustainability*(3-6).* Sustainability is a concept describing mankind's ability to create a world for humans and non-humans that environmentally, socially, and economically provides for a current population's needs without damaging the ability of future generations to take care of themselves. Sustainability is also a gauge of the extent to which policies and management align with the principles and philosophies of sustainable development. It can also be envisioned as an idealized realm or goal where all essential criteria are fulfilled to support ecosystems and uphold human well-being*(4).*

In healthcare, the term "sustainability" encompasses concepts of renewability, energy efficiency, non-toxicity, minimally invasive practices, reduced carbon footprint, effective waste management, and the design of hospitals and offices in alignment with eco-friendly principles*(4,7).*

Sustainable Oral Healthcare

All sustainable healthcare systems consider the long-term social and environmental impacts of health services using available resources effectively and addressing the health rights and needs of future generations*(4,7).* The fundamental elements of sustainable healthcare are low-carbon care models, eco-friendly transportation, healthcare facilities with green buildings, the reduction, recycling, and reuse of medical waste, as well as the procurement of low-carbon products and services, which include pharmaceuticals and medical equipment. Such systems aim to provide healthcare services with an environmentally, socially, economically, and ethically responsible approach*(4,6).*

Oral healthcare is essential for overall health, well-being, and quality of life. This needs to be delivered ethically, with high levels of quality and safety and be environmentally sustainable. In this way, the healthcare opportunities of current and future generations are respected and protected by actively minimizing negative environmental impacts*(8).* Sustainable oral healthcare involves maintaining optimal oral health while mitigating the adverse environmental and societal effects linked to dental care. This principle is closely connected to the overarching field of sustainable healthcare, highlighting the significance of delivering healthcare services in a manner that diminishes waste, lowers the carbon footprint, and fosters fair access to care*(8,9).*

In the delivery of oral healthcare, four domains “preventive care”, “operative care”, “integrated care” and “ownership of care” have great importance. By engaging with these four domains, oral health professionals can provide effective, high-quality, and environmentally sustainable care*(8,10).*

The dental practice consumes many resources with an environmental impact, such as the energy and water used by the equipment. Also, this practice produces large quantities of plastic waste more x-ray radiation, and the waste from products involving metals like mercury. However, dentists are increasingly recognizing the need to provide care sustainably, by minimizing the impact on natural resources and contributing to the transition to an eco-friendly practice*(11-13).* Climate change and environmental pollution are among the greatest health threats affecting the planet, humanity and biodiversity. This is recognized in the 2030 United Nations Agenda for Sustainable Development, which includes an urgent call for action from all sectors. The entire oral healthcare community, including clinical professionals and industry, recognizes that there is a responsibility to deliver products and interventions sustainably improve oral health. With “Sustainability in Dentistry” project, FDI-World Dental Federation supports the provision of eco-friendly dental care and an environmentally sustainable practice. Eco-friendly dentistry (or green dentistry) mainly focuses on reducing waste and pollution, conserving energy, water, and money, using reusable and biodegradable materials, and promoting increased use of hightechnologies in dental clinics*(8,14-16).*

Sustainability is about the sensible and responsible use of natural resources to avoid depletion and maintain an ecological balance. From a sustainability perspective, the dental team should ensure that waste is dealt with in the most ecologically sound way. Ensuring clinical waste is kept to a minimum will reduce the carbon emissions associated with incineration. Recycling will help reduce the depletion of natural resources in terms of paper, plastic and glass products, with associated lower carbon emissions than landfill. Reduction of these materials is best achieved through the delivery (by clinicians) and maintenance of good oral health, focused on prevention and high-quality interventions. The dental team have legal and professional responsibilities to ensure that waste is correctly managed in a way that does not cause pollution of the environment or harm to human health*(10-13,17).*

Many dentists are indeed placing a significant emphasis on sustainability, implementing practices such as utilizing environmentally friendly dental supplies and equipment or renovating their clinics to be more energy efficient*(18,19).* These efforts not only contribute to reducing environmental impact but also align with the goal of providing sustainable oral healthcare. Furthermore, advancements in oral health and overall well-being can be achieved through a proactive approach that includes preventive measures, regular screening, and monitoring of systemic health conditions. By integrating environmentally friendly practices into these aspects of care, dental professionals can promote both oral health and environmental sustainability simultaneously. Sustainability in dentistry represents a broader commitment to social and environmental responsibility. Dentists play a crucial role in safeguarding the well-being of future generations by respecting the right to a world with sufficient natural resources. By embracing sustainability as a core principle, oral health professionals can contribute to creating a healthier and more sustainable future for all*(8,14).*

In accordance with the FDI Vision 2030 document which calls for urgent action on oral health, the principal goal of oral health professionals is to promote universal oral health for diseases that are largely preventable and/or treatable in the early stages. The provision of oral healthcare, in the form of prevention, therapeutic interventions, or long-term maintenance, creates pollution and a significant carbon footprint. Oral healthcare providers have an ethical and moral responsibility to manage the impact of dental activities on the environment and ensure that they do so in a sustainable manner*(10,17).*

Sustainable Oral Healthcare from Ethical Standpoint

The environmental footprint of healthcare and the complexity of sustainability raises ethical dilemmas concerning healthcare's environmental guardianship. The commitment to the well-being of the Earth's ecosystems suggests that healthcare institutions and professionals need an appropriate ethical approach to mitigate or eliminate possible harmful effects*(1).* Ethics provides the foundation on which a principled framework for building a holistically healthier world can rest*(20).* Sustainability in healthcare from an ethical perspective involves balancing the current needs of patients and communities with the long-term preservation of resources, environmental health, and social equity. This approach acknowledges that healthcare systems must not only deliver quality care to individuals but also address the broader impact of their actions on society and the environment*(9,21).*

In 1927, Fritz Jahr introduced the concept of bioethics (German: bio-ethik), emphasizing moral responsibilities extending beyond humans to encompass all life forms. Nearly half a century later, in 1971, Van Rensselaer Potter adopted the term "bioethics" in English to articulate a life-ethic suited for an industrialized society within a fragile ecosystem. Potter envisioned bioethics as inherently practical, grounded in ecologically sustainable living that embraces the interconnectedness of Earth and its inhabitants. Despite its environmental roots, the trajectory of bioethics shifted notably after Beauchamp and Childress proposed "biomedical ethics" in 1979. Their framework, centered on the patient-physician relationship and delineated by principles of autonomy, beneficence, non-maleficence, and justice, became widely adopted. This approach led to a conflation of "bioethics" with "biomedical ethics", overshadowing its ecological underpinnings. This oversight prompted the emergence of a distinct field known as environmental ethics, seeking to reassert the ecological origins of bioethics*(22-24).*

Bosworth et al. argue that the prevailing paradigm concerning human-nature relations tends to be anthropocentric. However, contemporary perspectives advocate for a more holistic understanding of our relationship with nature, favoring an ecocentric approach over an anthropocentric one. Within this framework, the concept of bioethics has expanded to encompass environmental ethics, reflecting a broader commitment to respecting all forms of life. This entails moving beyond solely anthropocentric viewpoints to incorporate biocentric and environmentally centered worldviews. Unlike anthropocentric approaches, which primarily focus on human interests, environmental ethics recognize the intrinsic value of nonhuman nature and advocate for the protection and preservation of ecosystems*(25).*

Environmental ethics emphasizes the interconnectedness of human health, environmental integrity, and the ethical considerations necessary for ensuring the well-being of all life forms on Earth. Environmental ethics is the disciplined study of the morality of the relationship between human beings and the environment, including especially other living things (plants and animals) and natural resources vital to the well-being of living things, such as the quality of air and water. An important connection between environmental ethics and bioethics is ethical reasoning about the impact of changes in the environment -both natural changes and changes resulting from human behavior- on health*(26).* Contemporary environmental ethics go beyond simply extending moral principles intended for human use to encompass other living beings, ecological systems, and the planet. They offer frameworks for considering nonhuman nature, humans, animals, the future, and the planet in interconnected ways that acknowledge the complex web of life. At the core of environmental ethics is the recognition of species interdependence, the interconnectedness of ecologies, and the threats to their survival. Understanding these relationships is fundamental to determining the "worth" of actions and entities within environmental ethics. Environmental ethics expanded its scope to encompass a wide array of topics, including sustainability, deep ecology, social ecology, and ecofeminism. Environmental ethics not only delves into theoretical aspects but also has practical applications, influencing the management and use of natural resources*(20,27).*

The environmental ethics in oral healthcare sustainability include many important key aspects. For instance, oral healthcare facilities can reduce their environmental footprint by implementing energy-efficient practices, reducing waste generation, and adopting sustainable procurement policies. Environmental ethics in oral healthcare advocate for the adoption of eco-friendly dental practices, such as using renewable energy sources, implementing green building designs, and reducing the use of harmful chemicals and pollutants. Oral healthcare providers have a responsibility to prevent pollution and minimize environmental harm associated with dental procedures, waste disposal, and the use of pharmaceuticals. Environmental ethics in oral healthcare recognize the impact of environmental factors on human health and advocate for strategies to address environmental health risks. Dental professionals and organizations can advocate for policies that promote environmental sustainability and protect public oral health, including supporting legislation to reduce greenhouse gas emissions and strengthen environmental regulations*(10,17,28).*

Sustainable oral healthcare from an environmental ethics perspective involves some important principles which that focus on promoting oral health while minimizing negative impacts on the environment and fostering equitable access to dental care. Here are some key ethical considerations related to sustainable dentistry*(1,8,15,16,18,19,28-31)*:

1.Responsibility to future generations: Ethical considerations in oral healthcare sustainability encompass the duty to preserve resources. Embracing sustainability demonstrates a commitment to using resources efficiently and ensuring they are available for future generations.

2. Health Equity: Sustainable dental clinics prioritize preventive care and community education, promoting better oral health for all. This aligns with ethical principles of fairness and social justice by improving access to dental care and reducing health disparities.

3. Equitable Access to Dental Care: Ensuring equitable access to dental care is an ethical imperative in sustainable dentistry. Dental professionals should strive to provide care to underserved and vulnerable populations, advocating for policies that promote oral health equity and reducing disparities in dental care access.

4. Preventive Care: Emphasizing preventive dental care aligns with ethical principles in sustainable dentistry. Preventing dental issues through patient education and regular check-ups reduces the need for more resource-intensive and potentially harmful interventions.

5. Continuing Education: Dental professionals have an ethical responsibility to stay updated on sustainable dental practices. Participating in continuing education programs that highlight environmentally responsible techniques and materials helps foster ethical practices.

6. Patient-Centered Care: Ethical sustainable dentistry places patients at the center of dental care decisions. It involves informed consent, respect for patient autonomy, and providing education to patients about sustainable oral health practices they can adopt at home.

7. Waste Reduction and Recycling: Reducing waste in healthcare is both ethically and environmentally important. Sustainable dentistry promotes waste reduction and recycling efforts within dental offices. Implementing strategies to minimize single-use plastic waste and recycling dental materials whenever possible are essential. Waste reduction includes not only minimizing physical waste but also avoiding unnecessary tests, treatments, and prescriptions that may have adverse effects on patients and contribute to rising healthcare costs.

8. Resource allocation: Healthcare institutions face challenges in allocating finite resources, such as medical supplies, energy, and water. Ethical decision-making in resource allocation requires prioritizing those treatments and interventions

that provide the greatest health benefits while considering the environmental impact of resource consumption.

9. Environmental impact: Sustainable healthcare aims to minimize its environmental footprint. From reducing greenhouse gas emissions and hazardous waste to adopting eco-friendly practices in hospital operations, healthcare systems should prioritize environmental stewardship to protect public health and ecosystems. Dental professionals should strive to use dental materials that are biocompatible and have a lower impact on the environment.

Conclusion

Adopting a sustainable approach to healthcare from an ethical perspective requires a holistic view that balances short-term patient needs with long-term environmental and societal impacts. By integrating these ethical considerations into oral healthcare decision-making, dental professionals can contribute to a more sustainable and socially responsible approach to oral healthcare, promoting positive impacts on patients, communities, and the environment. Concern for the health of the earth's ecosystems suggests that healthcare institutions and practitioners should reassess their practices to soften or eliminate harmful effects. At the same time, they should balance their environmental responsibilities with their obligations to serve the immediate needs of patients. Addressing the issue of balance requires combining considerations from both healthcare ethics and environmental ethics. Sustainable oral healthcare is the provision of equitable, ethical, high-quality, inclusive, and safe care with appropriate, effective and efficient use of resources. Through this, the healthcare opportunities of current and future generations are respected and protected by actively minimizing negative environmental impacts.

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THE INFLUENCE OF MANAGED CARE ON THE PHYSICIAN'S PERCEPTION OF PROFESSIONAL AUTONOMY: A SCOPING REVIEW

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Abstract: The present study undertakes a scoping review on the influence of managed care on the perception of physicians' professional autonomy to determine how many studies there are in the literature on the perception of decreased physician's professional autonomy with the introduction of managed care, the consequences of this for the health system and studies that indicate possible coping strategies for this problem.

Online databases were used to identify articles published from 2017 to 2021.

Two articles related managed care to a decrease in professional autonomy, six articles showed a relationship between independence and professional satisfaction, and three articles concluded that a decrease in autonomy contributes to physicians' rejection of managed care. Two articles related physicians' resistance to innovation in information technology (IT) due to fear of reduced autonomy. One article related the decrease in autonomy to the decline in the supply of new professionals and three articles indicated that the management model focused on stimulating intrinsic motivators, such as professional autonomy, can generate promising results.

Although robust studies are showing that managed care interferes with the perception of the physician's professional autonomy with consequences for the health system, there is still a lack of studies that assess the best strategy for coping with this problem.

Keywords: professional autonomy, burnout, managed care, health care reform, professionalism

La influencia de la atención gestionada en la percepción de la autonomía profesional del médico: una revisión exploratoria

Resumen: El presente estudio realiza una revisión de alcance sobre la influencia de la atención gestionada en la percepción de la autonomía profesional de los médicos, con el objetivo de identificar cuántos estudios existen sobre la percepción de la disminución de la autonomía profesional de los médicos tras la introducción de la atención gestionada, las consecuencias de esto para el sistema de salud y los estudios que indican posibles estrategias de afrontamiento para este problema. Para ello se utilizaron bases de datos en línea para identificar artículos publicados entre 2017 y 2021.

De los estudios revisados, dos artículos relacionaron la atención gestionada con una disminución de la autonomía profesional, seis mostraron una relación entre la independencia y la satisfacción profesional, y tres concluyeron que la pérdida de la autonomía contribuye al rechazo de los médicos a la atención gestionada. Dos estudios relacionaron la resistencia de los médicos a la innovación en tecnología de la información (TI) con el temor a perder autonomía, mientras que un artículo relaciona la disminución de la independencia con la caída de la oferta de nuevos profesionales. Finalmente, tres indican que el modelo de gestión centrado en estimular motivadores intrínsecos, como la autonomía profesional, puede generar resultados prometedores.

A pesar de que existen estudios sólidos que demuestran la atención gestionada interfiere en la percepción de autonomía profesional y tiene consecuencias para el sistema de salud, todavía faltan estudios que evalúen las mejores estrategias para hacer frente a este problema.

Palabras clave: autonomía profesional, burnout, atención gestionada, reforma de la atención sanitaria, profesionalismo

A influência do cuidado gerenciado na percepção do médico de autonomia profissional: uma revisão de propósitos

Resumo: O presente estudo conduz uma revisão de propósitos na influência de cuidados gerenciados na percepção de autonomia profissional de médicos para determinar quantos estudos há na literatura sobre a percepção de diminuição da autonomia profissional de médicos com a introdução de cuidados gerenciados, as consequências disso para o sistema de saúde e estudos que indicam possíveis estratégias de enfrentamento desse problema.

Desenho. Bancos de dados online foram usados para identificar artigos publicados de 2017 a 2021.

Resultados. Dois artigos relacionam cuidados gerenciados com uma diminuição de autonomia profissional, seis artigos mostraram uma relação entre autonomia e satisfação profissional, e três artigos concluíram que uma diminuição na autonomia contribui para a rejeição dos médicos de cuidados gerenciados. Dois artigos relacionaram a resistência de médico para inovação em tecnologia da informação (TI) devido ao medo de autonomia reduzida. Um artigo relacionou a diminuição na autonomia ao declínio no suprimento de novos profissionais e três artigos indicaram que o modelo de gestão focado em estimular motivadores intrínsecos, como a autonomia profissional, pode gerar resultados promissores.

Conclusões. Embora existam estudos robustos mostrando que os cuidados gerenciados interferem com a percepção de autonomia profissional de médicos com consequências para o sistema de saúde, ainda faltam estudos que avaliem a melhor estratégia para o enfrentamento desse problema.

Palavras chave: autonomia profissional, exaustão (burnout), cuidado gerenciado, reforma dos cuidados à saúde, profissionalismo

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Introduction

Managed care has contributed to major changes in physicians' relationships with patients and their role in the healthcare system*(1)*.

Industrialized nations are pursuing market-based financing models with a focusing on equity in access to care, quality of care, health status and efficiency*(2)*.

The objective of promoting the population`s health, and providing a good experience of patient care at a low cost is fundamental to improve the performance of the health system. However, doctors are not satisfied. Medical burnout is a growing concern worldwide*(3)*.

This suggests that in practice doctors are being neglected, despite being essential to the future development of Managed Care*(4)*.

Managed care reduced the level of professional satisfaction of physicians, and this is due not only to the reduction in income but also to the reduction of professional autonomy*(5)*.

Research shows that health system reforms, by interfering with professional autonomy, affected professions and professionalism in the health area. Professionalism is a work logic defined by high autonomy and self-control, governed by a code of ethics independent of management requirements*(6)*.

Before managed care, the healthcare system was underpinned by medical professionalism, with physicians enjoying high levels of autonomy*(6)*. However, doctors are increasingly being hired as employees by large healthcare organizations, a fundamental shift from the individual practice model of the past*(1)*.

This change led to a strong dependence on the material motivation of physicians and rigidity in following evidence-based medicine*(2)*.

Professional autonomy is the domain that professionals have over their work. The doctor's professional autonomy is divided into three categories: independence in clinical work; social and economic freedom from work; and power to influence organizational decisions*(7)*.

Clinical work independence refers to the ability to decide how to care for a patient without the intrusion of organizational procedures, financial concerns, or performance measurement systems. The social and economic freedom of work represents the ability of doctors to determine their movements, priorities, schedules and workload. The power to influence organizational decisions is related to the ability of physicians to participate in organizational and managerial choices and to influence the organization's strategic decisions*(7)*.

The physician's professional autonomy is directly related to career satisfaction, and this is reflected in the quality of care measured by prescription standards, adherence and patient satisfaction. Physician turnover has important financial implications, and the estimated cost of replacing a primary care physician ranges from $240,000 to $265,000*(1)*.

Physician career satisfaction influences the attractiveness of the medical profession, shaping the quantity and quality of the medical school entry pool, as well as the selection and distribution of specialties. Thus, satisfaction with a physician's career can shape the physician workforce*(1)*.

Medical burnout increases the rate of self-reported medical errors and is associated with lower patient satisfaction*(3)*.

The analysis of the influence of managed care on the perception of professional autonomy and its consequences for the health system is important for the elaboration of strategies capable of consolidating managed care and reducing physicians' rejection of reforms and innovations in the health system, and therefore being a broad topic, the scope review method was chosen for the preparation of this study.

Objective

This scoping review aims to examine the existing literature in the last five years

on the influence of managed care on the perception of physicians' professional autonomy to determine how many studies there are in the literature on the perception of decreased physician's professional autonomy with the introduction of managed care, the consequences of this for the health system and studies that indicate possible coping strategies for this problem.

Method

The methodology used in this research work was the scoping review. A scoping review synthesizes knowledge and incorporates a variety of study designs, to guide future research priorities*(8)*.

Our protocol was prepared according to PRISMA Extension for Scoping Reviews (PRISMA-ScR): checklist and explanation*(9)*, the final protocol was registered with the Open Science Framework on March 1, 2023

The scoping review is particularly useful for bringing together literature across disciplines with emerging evidence, addressing questions beyond those related to the effectiveness or experience of an intervention. Its value is in looking at a wider area to identify gaps, clarify key concepts, and report on the types of evidence that exist*(10)*.

The preparation of this article followed a process consisting of five steps: a) Identifying the research questions; b) Identifying the relevant studies valid for the investigation; c) Selecting the review studies; d) Mapping the data from the studies included in the review; e) Confronting, summarizing, and reporting the results*(8)*.

The guiding question of the research was: "What is the available evidence on physician's professional autonomy in managed care?".

This review was conducted in the PubMed/MEDLINE, Web of Science and Scopus databases. For this, the same descriptors were used for each of the databases of this review.

The controlled descriptors used were: "Professional autonomy", "Managed care" and "Physician", and for the combination of descriptors, the Boolean operators AND were used. The search was conducted using as time parameter the articles published in the last 5 years.

The inclusion criteria used were the articles should contain the words "Professional autonomy" and "Managed care"; present as objective the demonstration of the influence of managed care in the professional autonomy of the physician; be related to health organizations and/or to the provision of managed care.

Exclusion criteria were articles that addressed the themes of managed care and professional autonomy separately; that addressed professional autonomy, but not directly related to the medical profession; and that the theme of professional autonomy of the physician was not an important objective or result of the article.

The typology of the article did not configure as inclusion and/or exclusion criteria. The search for the study took place on 13 November 2021 using the advanced form.

Primary studies were selected, after analysis by two independent reviewers, according to the guiding question, inclusion and exclusion criteria. The instrument used to extract data from the included studies consisted of the following items: 1- article identification; 2- objective of study. Selection steps included identification, screening, eligibility and inclusion.

Results

Ninety-nine articles were found, 6 in the Web of Science, 3 in PubMed/MEDLINE and 90 in Scopus. After proceeding to the inclusion and exclusion criteria, two successive evaluations and disregarding duplicated articles, seventeen publications *(1,2,15-21,3,4,6,7,11-14)* were relevant for this review, since they met the study question and the pre-established criteria, as explained in the analysis flowchart (Figure 1)*(22)*.

The articles were analyzed according to the guiding question of the study and the selected articles are shown in the table 1 and 2 at the end of the article.

The articles included in this scoping review were published between the years 2017 to 2021, with 14 articles published in the last 3 years, suggesting a growing interest on the topic in recent years *(1,2,17,19-21,3,4,6,11-15)*.

Most articles were written by European authors,

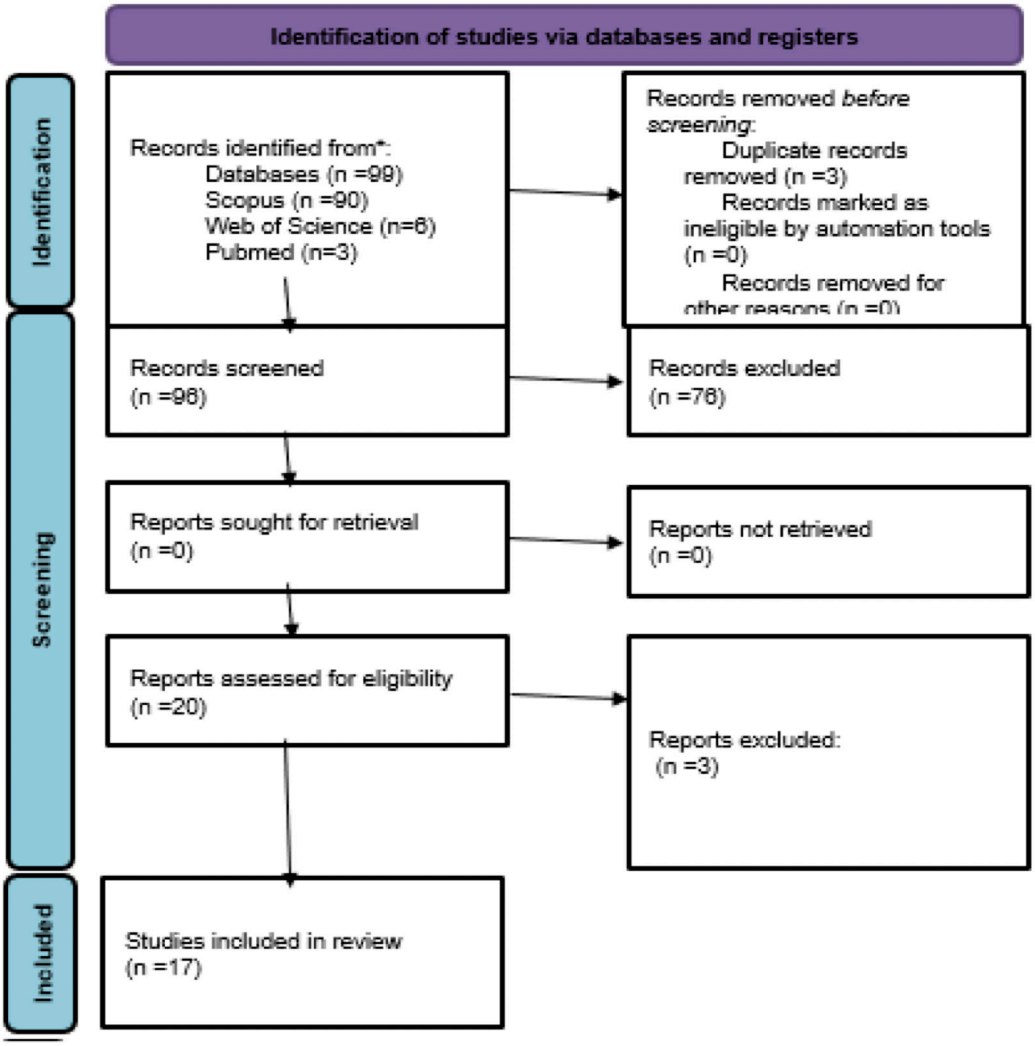

Figure 1 - analysis flowchart

10 in total*(2,4,6,7,12,15,17,18,20,21)* followed by American authors, with a total of 3 articles*(1,16,19)* and the authors of the remaining articles are from Japan(14), Taiwan(3), China(13) and Korea(11).

Five articles were published in medical journals*(1,3,14,17,18)*, seven articles were published in medical journals, seven articles were published in management and health systems journals*(2,4,7,11-13,16)*, four articles were published in social science journals *(6,19-21)* and one article published in an information system journal(15).

Six articles showed that the perception of decreased professional autonomy was related to decreased professional satisfaction*(7,11,13,1719)*, two articles related the managed care to the decrease of professional autonomy*(2,20)* and three articles concluded that the loss of professional autonomy contributes to the physician's rejection to managed care*(4,6,12)*.

Two articles related physicians' resistance to information technology (IT) innovation with the perception of decreased professional autonomy that innovation could cause*(15,21)*.

One article related the decrease of professional autonomy to the decline of new professionals*(14)* and three articles indicated that management and leadership model focused on primary well-being and stimulation of intrinsic motivators, such as professional autonomy may generate promising and longer-term results*(1,3,16)*.

The results found were diagrammed in the figure below (figure 2).

Discussion

In the broadest sense, professionalism is defined along three main dimensions: expertise, self-regulation, and an obligation to subordinate self-interest to the needs and interests of the client. Within the specific context of the medical profession, there has been an emphasis on altruism and the responsibility of physicians to embrace values that place the medical needs of patients above physicians' self-interest. High moral and ethical standards, recognition of and commitment to the needs of society and humanistic values such as integrity, reliability, respect, and empathy are also recognized as key elements of medical professionalism*(5)*.

Autonomy is related to professionalism on several levels. Collectively, it refers to the control of entry standards and the definition of terms of work. Individually encompasses both altruistic motivations and self-interest. Commitment to professional values and patient needs has made physicians achieve a unique social stature. Conveying a high degree of individual autonomy to control the terms and content of their work. In addition to aspects related to clinical decision-making, there are other prerogatives of control over work. Autonomy in this last aspect, although not related to patient care, remains a highly valued privilege among physicians*(5)*.

The physician´s professional autonomy has three dimensions: independence from clinical work; social and economic freedom from work; and power to influence organizational decisions*(7)*.

Clinical work independence is the physician's ability to decide how to care for the patient without

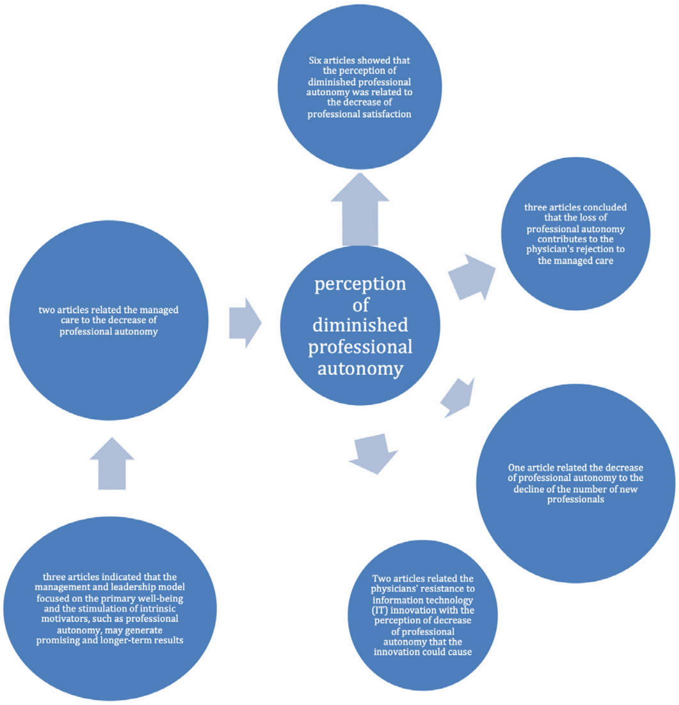

Figure 2. results diagram

being constrained by organizational procedures, financial concerns, or performance measurement systems*(7)*.

Social and economic freedom from work is control over earnings, and the nature and volume of the task. Represents physicians' ability to determine their priorities, schedules, and workload. The arrangements of a health system greatly influence this aspect. The social and economic freedom of a state-employed physician in a country with universal health care is different from that available to a self-employed physician in a country with health insurance. The power to influence organizational decisions refers to the participation of physicians in the organization's strategic decisions*(7)*.

Health systems in all countries of the world have the need to reduce costs despite the aging of the population, the burden of treating chronic diseases and the high price of new health technologies*(20)*.

Managed care established a new level of organization in health care enabling cost containment and quality improvement*(23)*.

Managed care brought about a profound transformation in the architecture and process of providing health care, promoting a shift in focus from the individual relationship between doctor and patient to the existing relationship between health institutions and the population served. Thus, an organizational perspective was created in parallel with the individual performance of the physician, with considerable potential for conflict*(23)*.

Managed care has implemented process and organizational innovations to improve population health, reducing the per capita cost of care and improving the experience of patients receiving care*(19)*.

Process innovation means "the same product, but at a lower cost". It is often imposed on an industry by competitors and usually implies a faster pace of work. Organizational innovation often occurs in the form of vertical integration and focusing on someone's core skills sometimes requires outsourcing certain tasks*(21)*.

These innovations have brought numerous reforms in the financial incentives that drive the demand and supply of medical services, with the primary goal of shifting the volume-based purchasing system of health services to value-based purchasing of health care. This shift features value-based metrics for quality and efficiency. The underlying assumption behind these new payment structures, often referred to as payment for performance (P4P), is that they will lead to improved health by encouraging health professionals to closely adhere to clinical guidelines*(19)*.

Another reform of the health system was the creation of modular services and service packages. Service packages are designed to treat common and known diseases. In this modular service delivery zone, the availability of resources, service design, such as well-established treatment protocols and service component specificity, quality metrics, enabling technologies and provider service differentiation resources, is high. Consequently, service delivery operations offer greater opportunities for service co-creation, greater flexibility through the combination of components and higher levels of efficiency*(24)*.

These organizational policies, in addition to optimizing the cost-effectiveness of healthcare investments, can exert a powerful influence on the attitudes and experiences of physicians and patients as they interact, but can misrepresent the behavior of healthcare organizations*(23)*.

If sometimes the imperative of profit imposed on hospitals by market-oriented policies is responsible for their distorted behavior, the medical practice itself has also been submitted to the logic of insurance companies ("managed care" for profit) by temporary contracts and "preferred provider". The most negative impacts that "managed care" can have on the quality of medical care lie in its rigid restrictions on physicians' professional autonomy, considering that this autonomy is important for health care to be biopsychosocial; central dependence on physicians' material motivation, through fee-for-service, pay-for-performance, combination of pay and other plans, and inducing fragmentation of health services, which makes communication, clinical coordination, continuing medical education and evaluation across institutional divisions difficult; and tendency to make the application of evidence-based medicine too rigid and commercial*(2)*.

While most physicians extract great meaning and purpose from their work, many also feel as if they are the "wheel cogs" of austere corporations that care more about productivity and finances than compassion or quality. Physician performance is now evaluated by a host of metrics (e.g., cost measures, patient satisfaction scores, how quickly they sign notes or respond to messages in the electronic health record inbox) that can overshadow the appreciation and respect of patients and colleagues who have traditionally served as physicians' primary source of feedback. These tactics can make physicians feel disrespected and micro-managed by a bureaucracy that does not recognize the nature of their work. The problem is compounded by extensive regulatory oversight, administrative burden, the implementation of suboptimal electronic health records used to enforce supervisory mandates, and other factors that can distort the meaning and purpose of work*(1)*.

Professional autonomy is a privilege of physicians and for this reason they resist changes that threaten them*(15)*.

Exhausted physicians are less empathetic, are more likely to make mistakes and prescribe unnecessary medications or tests, and their patients report lower levels of satisfaction and have longer post-discharge recovery times. Other health professionals, such as nurses, also report lower levels of satisfaction when working with burnt-out physicians. Burnout represents a high cost for health organizations in early retirement. Physicians lost to burnout cost well over $200,000 to replace. A 2012 population survey of general practitioners found that 45% reported at least one of the three symptoms of burnout, and these rates are increasing and suggest an impending crisis*(16)*.

Job satisfaction is an important consideration for medical graduates to choose a specialty, and the high rate of Burnout in some medical specialties may contribute to a shortage of professionals*(14)*.

Dissatisfaction with the profession and the perceived loss of professional autonomy also act as the main threats perceived by physicians to the implementation of innovations, including health information technology innovations, and direct impact on user resistance, where the more physicians and nurses perceive the loss of professional autonomy, the more likely they are to resist these innovations*(15)*.

The preservation of professional autonomy facilitates the implementation of innovations such as information technology. These innovations deliver services, and their operation is enhanced when each actor acts autonomously within the clinical guidelines developed by the institution. Professional autonomy helps stakeholders make the best clinical decisions*(24)*.

Conclusion

Job satisfaction is an important means of self-realization and quality of life, in addition to increasing employee productivity and having a long-term positive impact on the institution*(11)*.

Medicine is a highly gratifying occupation, but with great potential to generate stress, as any mistake can be fatal. A doctor is an important part of the health care system*(11)*.

Physicians' professional satisfaction is related to the reduction of medical expenses and the stability of the health system's workforce. Thus, job satisfaction for physicians is not just a personal issue but a health system-wide issue*(11)*.

The understanding about the factors that influence the physician's job satisfaction should be better understood. The organismic integration theory classifies the motivating factors of job satisfaction into intrinsic and extrinsic*(3)*.

Intrinsic motivators (IM) are when involvement in an activity is purely for its intrinsic pleasure or meaning. Contributors to intrinsic motivators are competence (the belief that the task is achievable), autonomy (opportunity to decide how to accomplish the task) and relatedness (task to some larger meaningful goal). Intrinsic motivators are robust in inspiring sustained and persistent effort and are considered the pinnacle of self-determination. Extrinsic motivators include financial incentives, titles, and awards*(19)*.

Intrinsic motivators, including autonomy, may increase job satisfaction, while poor extrinsic motivators, such as low pay, may lead to job dissatisfaction, but better extrinsic motivators may not lead to higher job satisfaction*(3)*.

Job satisfaction increases when doctors think that their autonomy is guaranteed*(11)*.

Professional autonomy is the ability to control the organization and terms of one's work. Today, the image of the doctor is still influenced by professionalism and its consequent autonomy*(13)*.

However, almost all developed countries are seeking better and more efficient ways to deliver medical services, and their health systems are in processes that reconfigure professional practice. The managerialism present in healthcare reforms establishes actions that are perceived as strengthening management control and economic rationalities, as opposed to professional autonomy, in decision-making*(20)*.

Value-based purchasing of health services is premised on the "triple aim" of bringing about improvements in the quality of health care, reducing the per capita cost of care and improving patients' experience of receiving care. The "triple aim" approach has escalated the amount, intensity, and pace of clinical work, reducing physician autonomy, resulting in negative effects on job satisfaction and occupational well-being*(19)*.

Managerialism in healthcare organizations can therefore be interpreted as a form of de-professionalization within the medical profession, as doctors lose power due to the loss of autonomy through better management control*(20)*.

Dissatisfaction and the perceived loss of professional autonomy are the main threats perceived by physicians that generate resistance to the implementation of information technology*(5,6,15)*. The dissatisfaction and the perceived loss of professional autonomy are the main threats perceived by physicians that generate resistance to the implementation of information technology, and in a similar way may be associated to the physicians' resistance to the implementation of health system reforms and the implementation of New Public Management policies, since many physicians feel threatened by giving up part of their professional autonomy in the course of managed care*(4)*.

On the other hand, physicians who perceive that the health organization preserves their autonomy will recognize an organizational image that preserves the continuity of their self-concept and increases their self-esteem, thus creating a strong organizational identification*(13)*.

Encouraging explicit recognition by health systems of the duty to include medical professional care, in the already established policy of patient-centered care, may reduce physician professional dissatisfaction and Burnout, and decrease reliance on financial stimuli to promote physician support*(16)*.

However, we still have few works that analyses the strategies to achieve this goal and compare the results with other forms of managerialism more dependent on extrinsic motivators.

This scoping review shows that managed care can influence physicians' perception of professional autonomy and found articles that show that the decrease in physicians' professional autonomy can have negative consequences for health system reforms, but evidence on the best ways to mitigate this problem is still limited.

Ethics approval and consent to participate

Not applicable.

Consent for publication

Not applicable.

Availability of data and materials

Not applicable.

Competing interests

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Table 1 - Characterization of the articles chosen

Author	Article Title	Magazine	Year of publication	Author's parents	Type of article
Ehlert, A; Oberschachtsiek, D.	Why do German physicians reject managed care?	Int J Health Plann Mgmt	2019	Germany	Original Article
Unger, JP; Paepe, P.	Commercial Health Care Financing: The Cause of U.S., Dutch, and Swiss Health Systems Inefficiency?	International Journal of Health Services	2019	Belgium	Original Article
Henrich, P; Bolter, R; Wensing, M.	Influences on Physicians' Participation in Coordinated Ambulatory Cardiology Care: A Mixed-Methods Study.	International Journal of Integrated Care	2020	Germany	Original Article
Zweifel, P.	Innovation in health care through information technology (IT): The role of incentives.	Social Science & Medicine	2021	Austria	Original Article
Kameyama, N; Nagai, H; Ikoma, N.	Job Characteristics Affecting Japanese Surgeons' Satisfaction Levels.	Journal of Surgical Research	2021	Japan	Original Article
Shanafelt, T; Trockel, M; Rodriguez, A; Logan, D.	Wellness-Centered Leadership: Equipping Health Care Leaders to Cultivate Physician Well-being and Professional Fulfillment.	Academic Medicine	2021	USA	Original Article
Tung, YC; Chou, YY; Chang, YH; Chung, KP.	Association of intrinsic and extrinsic motivating factors with physician burnout and job satisfaction: a nationwide cross-sectional survey in Taiwan.	BMJ Open	2020	Taiwan	Original Article
Alohali, M; Carton, F; Oconnor, Y.	Investigating the antecedents of perceived threats and user resistance to health information technology: a case study of a public hospital.	Journal of Decision Systems	2020	Ireland	Original Article
Agartan, IT.	Conceptualizing professional and public interest in the context of Turkey's health care reforms.	International Journal of Sociology and Policy	2019	Turkey	Original Article
Jin, Y; Wang,h; Wang, D; Yuan,B.	Job satisfaction of the primary healthcare providers with	Human Resources for Health	2019	China	Original Article

	expanded roles in the context of health service integration in rural China: A cross-sectional mixed methods study.				
Rosta, J; Aasland, OG; Nylenna, M.	Changes in job satisfaction among doctors in Norway from 2010 to 2017: a study based on repeated surveys.	BMJ Open	2019	Norway	Original Article
Oh, Y; Kim, H; Kim, K.	Factors affecting Korean physician job satisfaction.	International Journal of Environmental Research and Public Health	2019	Korea	Original Article
Post, SG; Roess, M.	Expanding The Rubric of "Patient-centered Care" (PCC) to "Patient and Professional Centerd Care"(PPCC) to Enhance Provider Well-being.	HEC Forum	2017	USA	Original Article
Wilkesmann, M; Ruiner, C; Apitzsch, B; Salloch, S.	"I Want to Break Free"- German Locum Physicians Between Managerialism and Professionalism.	Professions & Professionalism	2020	Germany	Original Article
Waddimba, AC; Mohr, DC; Beckman, HB; Mahoney, TL; Young, GJ.	Job satisfaction and guideline adherence among physicians: Moderating effects of perceived autonomy support and job control.	Social Science & Medicine	2019	USA	Original Article
Scheepers, RA; Lases, LSS; Arah, AO; Heineman, MJ; Lombarts, KMJMH.	Job Resources, Physician Work Engagement, and Patient care Experience in an Academic Medical Setting.	Academic Medicine	2017	Netherlands	Original Article
Salvatore, D; Numerato, D; Fattore, G.	Physician's professional autonomy and their organizational identification with their hospital.	BMC Health Services Research	2018	Italy	Original Article

Table 2 - Categorization of the articles included

Author	Article Title	Objectives of the Article	Conclusion of the article
Ehlert, A; Oberschachtsiek, D.	Why do German physicians reject managed care?	To show which factors explain German doctors' rejection of managed care.	It showed that private patient participation, physician age, number of physicians in the specialty, administrative burden and loss of professional autonomy significantly increase the likelihood of physician rejection of managed care.
Unger, JP; Paepe, P.	Commercial Health Care Financing: The Cause of U.S., Dutch, and Swiss Health Systems Inefficiency?	To evaluate the performance of 3 industrialized nations that have pursued market-based health system financing models, with a focus on equity of access, quality of care, health status and efficiency.	It defends the hypothesis that health insurance is detrimental to access to health care and the health status of the population, and that the most negative impacts of managed care are its strong restrictions on professional autonomy, heavy reliance on doctors' financial motivation, fragmentation of health services and the very rigid application of evidence-based medicine.
Hennrich, P; Bolter, R; Wensing, M.	Influences on Physicians' Participation in Coordinated Ambulatory Cardiology Care: A Mixed-Methods Study	To identify the factors associated with medium participation and their relationship to the objectives of a managed care programmed for outpatient cardiology care in southern Germany.	The main motivation for participating in the programmed was financial and the reasons for not participating were mainly technical modifications, economic investment, and fear for professional autonomy.
Zweifel, P.	Innovation in health care through information technology (IT): The role of incentives.	Predict the circumstances in which patients, doctors, hospitals, health insurers and governments are likely to support healthcare innovation through IT.	It suggests that IT innovation enabling product innovation is welcomed by health professionals, while IT innovation enablement and organizational innovation are resisted by them for fear of losing professional autonomy.
Kameyama, N; Nagai, h; Ikoma, N.	Job Characteristics Affecting Japanese Surgeons' Satisfaction Levels	To characterize the work-related perceptions of medical surgeons and non-surgeons in Japan and their relationship with the career choice of new medical graduates.	Surgeons consider their work highly ethical and meaningful to patients, their sense of autonomy is lower than that of physicians in other specialties. Improving surgeons' working environments is an imminent necessity to prevent surgeon burnout and mitigate

			the decline in the number of new surgeons.
Shanafelt, T; Trockel, M; Rodriguez, A; Logan, D.	Wellness-Centered Leadership: Equipping Health Care Leaders To Cultivate Physician Well-being and Professional Fulfillment	To propose a new model of wellness-centered leadership that includes essential skills and qualities from the most important leadership philosophies, along with evidence on the relationship between leadership and physician wellness, promoting physician engagement and professional fulfillment.	It concludes that this wellbeing-centered leadership model relies primarily on intrinsic motivators (meaning, purpose, values and professional autonomy) to generate results, rather than focusing on extrinsic motivators (financial, titles and awards) that over time reduce professional motivation and contribute to forming disengaged professionals.
Tung, YC; Chou, YY; Chang, YH; Chung, KP.	Association of intrinsic and extrinsic motivating factors with physician burnout and job satisfaction: a nationwide cross-sectional survey in Taiwan	To systematically and simultaneously examine the association of intrinsic and extrinsic motivating factors with burnout and job dissatisfaction.	It concludes that promoting a work environment that supports intrinsic motivation and rewarding physicians fairly and equitably can reduce physician attrition and job dissatisfaction.
Alohali, M; Carton, F; Oconnor, Y.	Investigating the antecedents of perceived threats and user resistance to health information technology: a case study of a public hospital.	To investigate the perception of threats that lead physicians and nurses to resist the implementation of health information technology in a public hospital.	It concludes that the perception of dissatisfaction and the loss of professional autonomy are the main threats perceived by physicians and nurses in the implementation of health information technology in the hospital evaluated.
Agartan, IT.	Conceptualizing professional and public interest in the context of Turkey's health care reforms	To explore the relationship of professional interest and autonomy in the context of Turkey's healthcare reform, and to evaluate possible alternative explanations of why doctors may oppose reforms at various stages of the political process.	Doctors' opposition to Turkey's healthcare reform cannot be explained simply by the defense of their material interests or their restriction of autonomy, and among other factors it may be related to the damage in relation to their social reputation which was portrayed as greedy and selfish actors.
Jin, Y; Wang,h; Wang, D; Yuan,B.	Job satisfaction of the primary healthcare providers with expanded roles in the context of health service integration	To assess the association between the expanded roles of primary care physicians in managed care in China and their job satisfaction.	The increase in workload and decrease in proportional income, increase in work responsibilities, and low professional autonomy had a negative

	in rural China: A cross-sectional mixed methods study		impact on the job satisfaction of primary care physicians in China.
Rosta, J; Aasland, OG; Nylenna, M.	Changes in job satisfaction among doctors in Norway from 2010 to 2017: a study based on repeated surveys.	To assess the level of job satisfaction among general practitioners, hospital doctors and specialists in private practice in Norway between the years 2011 to 2017.	There was a statistically significant decrease in job satisfaction for general practitioners and hospital doctors in the period, the factors associated with this being workload, remuneration, job recognition and clinical autonomy.
Oh, Y; Kim, H; Kim, K.	Factors affecting Korean physician job satisfaction.	To assess the level of job satisfaction and the factors that interfere with job satisfaction among Korean doctors.	The factors that positively affected job satisfaction for doctors were maintaining positive relationships with patients through adequate consultation time, clinical autonomy, having healthy relationships with colleagues, good social reputation, adequate income and working hours.
Post, SG; Roess, M.	Expanding The Rubric of "Patient-centered Care"(PCC) to "Patient and Professional Centered Care"(PPCC) to Enhance Provider Well-being.	Propose expanding "patient-centered care" to "patient and professional-centered care" by making provider self-care an explicit part of the health system's mission and management strategies to decrease Burnout among health care providers.	It states that the proposed management change does not question the primacy of the doctor's commitment to patient welfare, nor the reduction of value and respect for patient autonomy, but it is a management strategy that reduces professional dissatisfaction and its consequences such as emotional exhaustion, depersonalization of patients and low personal fulfilment.
Wilkesmann, M; Ruiner, C; Apitzsch, B; Salloch, S.	"I Want to Break Free"- German Locum Physicians Between Managerialism and Professionalism.	To investigate the rise in the number of self-employed doctors in German hospitals and its relation to professionalism and managerialism.	The managerialism of organization decreases the professional autonomy of doctors who act as permanent employees of these organizations and consequently affects their professionalism, this has stimulated the increase in the number of autonomous doctors who provide temporary work in these hospitals with a higher level of professional autonomy. Thus, the tension between professionalism and managerialism existing at the organizational level is reconciled at the

			individual level by autonomous physicians.
Waddimba, AC; Mohr, DC; Beckman, HB; Mahoney, TL; Young, GJ.	Job satisfaction and guideline adherence among physicians: Moderating effects of perceived autonomy support and job control.	To investigate whether the perception of physicians regarding support for autonomy and work control interfered with job satisfaction and adherence to guidelines in a pay-for-performance context.	It concluded that payers who try to over-direct physicians can demotivate them and decrease their adherence to guidelines.
Scheepers, RA; Lases, LSS; Arah, AO; Heineman, MJ; Lombarts, KMJMH.	Job Resources, Physician Work Engagement, and Patient care Experience in an Academic Medical Setting.	To assess the relationship between the work engagement of doctors in an academic hospital and the perception of the patient experience of care.	Greater physician engagement at work did not translate in this study into better care in the patient experience. From the physician's perspective professional autonomy and the opportunity for learning stimulate their engagement at work.
Salvatore, D; Numerato, D; Fattore, G.	Physician's professional autonomy and their organizational identification with their hospital.	To study the interaction between doctors' professional identity, their organizational identity, and the role of professional autonomy in these processes of social identification.	It suggests that organizations should support the or+D14:D18ganisational and economic autonomy of their doctors to design an organizational identity that preserves the continuity of professional identity.

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THE IMPORTANCE OF OVERLAPPING BIOETHICS AND BUSINESS ETHICS IN MANAGED CARE: A SCOPING REVIEW

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Abstract: Implementing diagnostic and therapeutic procedures that use advanced technologies in clinical practice has made medicine assume the responsibility of rationally using these modern and scarce resources. The development of managed health care has contributed to the emergence of ethical dilemmas that go beyond the ability of business ethics or bioethics alone to find answers.

This article examines the existing literature on the importance of overlapping bioethics and business ethics in crafting the moral foundations of managed care.

A scoping review was carried out with an analysis of articles published on the theme “Bioethics” and “Business Ethics” related to health organizations and health management.

The search identified 156 articles. After applying the eligibility criteria, 11 articles were selected.

The 11 articles highlighted the economics of health and health as a type of business. They presented the objective of demonstrating the importance of overlapping the disciplines of bioethics and business ethics in forming the ethos on which the health system will be based in this market economy context.

This scoping review reinforces the importance of the approach of bioethics and business ethics in health management.

Keywords: bioethics, business ethics, organizational ethics, health organizations, managed care.

La importancia de la superposición de la bioética y la ética empresarial en la atención gestionada: una revisión del alcance

Resumen: La implementación de procedimientos y diagnósticos terapéuticos que utilizan tecnología avanzada en la práctica clínica, ha hecho que la medicina asuma la responsabilidad de utilizar racionalmente estos escasos recursos. El desarrollo de la atención médica administrada ha contribuido al surgimiento de dilemas éticos que escapan de la ética empresarial o la bioética para encontrar respuestas.

Este artículo analiza la literatura existente sobre la intersección de la bioética y la ética empresarial en la construcción de los principios morales que sustentan la atención administrada.

Para ello, se realizó una revisión exploratoria mediante un análisis de artículos publicados sobre el tema: “Bioética” y “Ética empresarial”, relacionados con las organizaciones de salud y la gestión de la salud. La búsqueda inicial identificó 156 artículos, de los cuales, y luego de aplicar los criterios de elegibilidad, se seleccionaron 11 para el análisis.

Los estudios revisados destacaron la importancia de la economía de la salud y la salud como un tipo de negocio y demostraron cómo la convergencia entre la bioética y la ética empresarial es clave para definir el ethos en el que se basará el sistema de salud en el contexto de economía de mercado. Esta revisión de alcance refuerza la importancia del enfoque de la bioética y la ética empresarial en la gestión de la salud.

Palabras clave: bioética, ética empresarial, ética organizacional, organizaciones de salud, atención médica administrada.

A importância da sobreposição da bioética e da ética empresarial no cuidado gerenciado: Uma revisão de propósitos

Resumo: A implementação de procedimentos diagnósticos e terapêuticos que utilizam tecnologias avançadas na prática clínica fez a medicina assumir a responsabilidade de usar racionalmente esses recursos modernos e escassos. O desenvolvimento do cuidado à saúde gerenciado contribuiu para o surgimento de dilemas éticos que vão além da capacidade da ética empresarial ou da bioética por si só encontrar respostas.

Objetivo. Esse artigo examina a literatura existente sobre a importância de sobrepor bioética e ética empresarial na elaboração dos fundamentos morais do cuidado gerenciado.

Desenho. Realizou-se uma revisão de propósitos com análise de artigos publicados sobre os temas “Bioética” e “Ética Empresarial” relacionados a organizações de saúde e gestão da saúde.

Resultados. O levantamento identificou 156 artigos. Depois de aplicar os critérios de elegibilidade, 11 artigos foram selecionados.

Os 11 artigos incluídos destacaram a economia da saúde e saúde como um tipo de negócio e apresentaram o objetivo de demonstrar a importância de sobrepor as disciplinas de bioética e ética empresarial na formação do ethos sobre o qual se baseará o sistema de saúde neste contexto de economia de mercado.

Conclusões. Essa revisão de propósitos reforça a importância da abordagem de bioética e ética empresarial na gestão de saúde.

Palavras chave: bioética, ética empresarial, ética organizacional, organizações de saúde, gerenciamento de cuidados

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Highligths

- Managed care is a business model guided by business ethics.
- The business perspective contributes to the creation of cost-effective services.
- Consumers and patients are different and therefore business ethics are insufficient.
- The principles of bioethics contribute to maintaining the organization's focus on patient.
- The physician is also responsible for the fair distribution of resources.

Introduction

The enormous power of medicine conferred by the knowledge of life and death made it necessary to create a deontological code based on the physician's notion of responsibility for the well-being of his patient, being the basis of the physician's social responsibility*(1,2)*.

Technological advances have raised the cost of diagnostic and therapeutic methods, and as a result, medicine, which traditionally focused on the well-being of the individual patient, now has to rationally and effectively use these scarce and modern resources, establishing that certain limits were imposed on the accessibility of these tools*(1)*.

The claim that physicians should not weigh the costs of their clinical decisions has become an economic absurdity that would bankrupt any health-care system*(3)*.

In the health system, the well-being of a single patient becomes part of the complex strategy game that involves the need to respect the well-being of other patients, current and future. The scarcity of resources made it necessary to integrate the traditional concept of medical ethics with the principles of business health management that involve the efficient use of medical procedures. This has led health organizations to manage care through a variety of mechanisms, including financial incentives and regulation of use, and has redefined the concept of good quality in health services, introducing the concept of cost-effectiveness, and these organizational policies can have a powerful influence on the behaviors and experiences of physicians and patients as they interact*(1,4)*.

However, good quality and cost-effectiveness do not always go together in all cases, and some health care cannot be delivered cost-effectively*(1)*.

Market laws can make managed care perfectly efficient from an economic point of view but ethically unfair by failing to provide basic care to the worst off; for example, a certain diagnostic or therapeutic procedure may no longer be offered to patients because it is not cost-effective*(5)*.

Managed care, when defining its obligations unilaterally, with socioeconomic priorities, subordinating medical treatment to the effective management of all resources, can result in the objectification of the patient. The patient is treated as a recipient of algorithmic procedures or simply as a "consumer" of the health service. This can lead to a failure to consider the patient's vulnerability and the ethical difference between the patient and the consumer*(1,5)*.

Collective decision rules and processes are increasingly supplanting shared discussions and decision-making by the physician-patient dyad in managed care. The institution-patient relationship is increasingly eliminating the intermediary, that is, the physician*(6)*.

Suppose health care should not be considered a commodity and essentially represents a moral enterprise. In that case, it is necessary to evaluate the emergence of managed care with its care management processes from an ethical and not just an operational perspective. But when institutions, such as insurance companies and hospitals, take over the roles formerly performed by physicians, business ethics and economic theory, rather than medical ethics, provide the guidelines. However, business ethics do not seem to provide the necessary basis to protect patients or guide health*(4,7)*.

Although the principle of fairness is frequently referred to in the business ethics literature, there is little mention of the principles of autonomy and beneficence(8).

The ethical obligation to care first for the patient's well-being, which lies at the heart of medicine, can also be fruitful in an ethical approach to managed care. So patients can expect managed care to respect the ethical duties of autonomy, beneficence, non-maleficence, and justice*(5)*.

If managed care has a significant business component, it seems that the fields of bioethics and business ethics should overlap. Thus, there is good reason to work towards greater integration of these two distinct fields, at least in the area of overlap, and prepare ethics committees to say when cost factors outweigh other considerations and when they do not*(6,9)*.

Objective

This scoping review aims to examine the existing literature on bioethics and business ethics in healthcare organizations and managed healthcare delivery.

Method

The scoping review method was used. A scoping review is a form of knowledge synthesis that incorporates a range of study designs to comprehensively summarize and synthesize evidence, providing guidance for future research priorities*(10)*.

The aim was to map the key concepts that underpin an area of research, particularly useful for gathering literature in disciplines with emerging evidence, as they are well suited to address issues beyond those related to the effectiveness or experience of the intervention. The value of an evidence-based practice is examining a broader area to identify gaps in the research knowledge base, clarify key concepts, and report on the types of evidence that exist*(11)*.

Our protocol was prepared according to PRISMA Extension for Scoping Reviews (PRISMA-ScR): checklist and explanation*(12)*, the final protocol was registered with the Open Science Framework on May 1, 2023.

The preparation of this article followed a process consisting of five steps: a) Identification of research questions; b) Identify relevant studies valid for research; c) Selection of review studies; d) Mapping of data from studies included in the review; and e) Compare, summarize, and report the results*(10)*.

The guiding question of the research was: "What is the available evidence on the interconnection of bioethics and business ethics in health organizations and managed care?".

This review was carried out in the PubMed / MEDLINE, Web of Science, and Scopus databases. For this, the same descriptors were used for each review database. The controlled descriptors used were: "Bioethics" and "Business ethics", and the Boolean operators AND were used to combine the descriptors.

The inclusion criteria used were: articles whose objective is to demonstrate the importance and/or necessity of interconnecting the disciplines of bioethics and business ethics; be related to healthcare organizations and/or managed care.

Exclusion criteria were defined as articles that addressed the topics of bioethics and business ethics separately, that did not relate to healthcare organizations and/or Managed care, and that the topic of interconnecting bioethics and business ethics was not the main objective.

The typology and language of the article were not inclusion and/or exclusion criteria. The search for the survey took place on October 07, 2022.

After identification, the primary studies were selected according to the guiding question and the previously defined inclusion and exclusion criteria. This step was performed by two reviewers independently. The instrument developed to extract and analyze data from the included studies was composed of the following items: 1) article identification; and 2) object and/or question and/or objectives of the study. Study selection steps included identification, screening, eligibility, and inclusion.

Results

We found 156 articles: 36 in the Web of Science, 109 in PubMed/MEDLINE, and 11 in Scopus. After proceeding with the inclusion and exclusion criteria, two successive evaluations and disregarding duplicate articles, 11 publications*(1-9,13,14)* were relevant for this review. These 11 studies met the study question and the criteria pre-established, as explained in the analysis flowchart*(15)* (Figure 1).

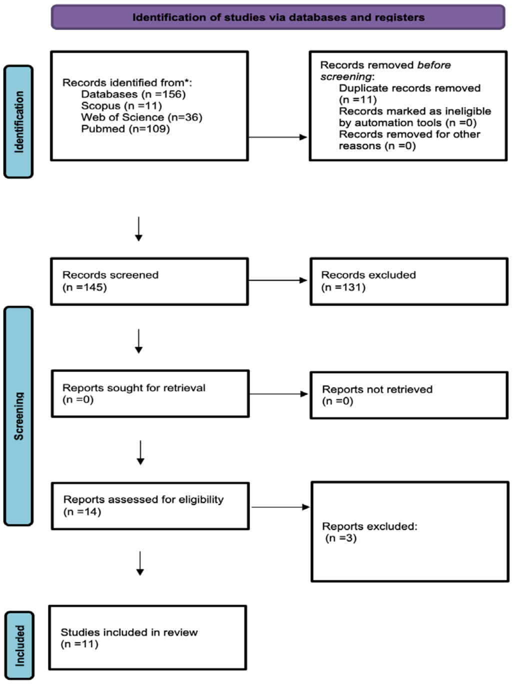

Figure 1 . Article analysis flowchart.

The articles were analyzed according to the guiding question of the study, and the selected articles are shown in the table below (Table 1).

The articles included were published between 1997 and 2021, with the majority (n = 8; 72.7%) having been published for more than 10 years. Most articles (n = 7; 63.3%) were written by American authors*(2-4,7,9,13,14)*, and other articles are from Australia (n = 1; 9.1%) (8), Belgium (n = 1; 9.1%) (5), Poland (n = 1; 9.1%) (1), and Canada (n = 1; 9.1%) (6) (Table 1).

The articles are mostly theoretical (n = 10; 90.9%). Regarding the focus of the journal where they were published, a portion of the articles (n = 3; 27.3%) were published in medical ethics journals(5,13,14); others in journals focused on business ethics (n = 2; 18.2%) (3,8) and in bioethics/philosophy journals (n = 2; 18.2%) (2,7)"mendeley":{"formattedCitation":"(2,7, and the remaining articles were published in journals of philosophy/medicine (n = 1; 9.1%) (1), health management (n = 1; 9.1%) (6), internal medicine (n = 1; 9.1%) (4), and health services (n = 1; 9.1%)(9).

All the articles highlighted the economic rationalization of health and health care as a type of business and had the objective of demonstrating the importance of overlapping the disciplines of bioethics and business ethics in the creation of the ethos on which the health system will be based in this market economy context. Based on the analysis carried out, central themes were observed, namely:

Contribution of bioethics to business ethics: Respect for the bioethical principles of beneficence, non-maleficence, autonomy, and justice by health organizations contributes to maintaining the organization's focus on the well-being of the patient*(4,5,8)*, helping to balance the mission to profit and deliver a quality service to society*(14)* and helping to analyze the moral consequences of adopting a market ethic in health care*(2)*.

Bioethics has demonstrated the diversity of patients' desires, and extending this logic of multiplicity of desires to shareholders will help managers to delimit the organization's ethical behavior*(3)*.

Organizational ethics is the discipline of study that can apply tools brought from bioethics to business ethics*(6)*, and ethics committees must be prepared to deal with organizational ethics*(9)* (Table 2).

Health as a market: There is a difference between consumers from other business areas and patients that can make it difficult to characterize health as a commodity, and this can reinforce the insufficiency of business ethics in being able to elaborate responses to all conflicts that may arise in the provision of managed care*(5)*, however. However, bringing a business perspective to the health system contributes to the creation of cost-effective services*(13)* (Table 2).

Contribution of the doctor and the institution to business ethics: The physician's responsibility is not limited to using the available means to perform the necessary therapy for the patient and extends to the fair distribution of scarce resources*(1)*.

Table 1 Categorization of articles

Author	Title	Journal	Year of publication	Article type	Author's country
Fisher J. (8)	Lessons for business ethics from bioethics.	Journal of Business Ethics.	2001	Theoretical article	Australia
Hardwig J. (3)	The Stockholder - A lesson for business Ethics from Bioethics?	Journal of Business Ethics.	2010	Theoretical article	USA
Werhane Patricia H. (13)	Review of The Business Ethics within Bioethics, by Leonard J. Weber.	The Hastings Center Report.	2002	Opinion article	USA
Van Campen LE, Poplazarova T, Therasse DG, Turik M, Biopharmaceutical Bioethics Working Group. (14)	Considerations for applying bioethics norms to a biopharmaceutical industry setting.	BMC Med Ethics.	2021	Theoretical article	USA
Raus K, mortier E, Eeckloo K. (5)	The patient perspective in health care networks.	BMC Med Ethics.	2018	Theoretical article	Belgium
Kwiatkowski W. (1)	Medicine and Technology. Remarks on the notion of responsibility in technology-assisted health care.	Med Health Care Philos.	2018	Theoretical article	Poland
Ells C, Macdonald C. (6)	Implications of organizational ethics to healthcare.	Health Manage Forum.	2002	Theoretical article	Canada
Pepin JF. (7)	Business ethics and health care: the re-emerging institution-patient relationship.	J Med Philos.	1999	Theoretical article	USA
Pellegrino ED. (2)	The commodification of medical and health care: the moral consequences of a paradigm shift from a professional to a market ethic.	J Med Philos.	1999	Theoretical article	USA
Eiser AR, Dorr Goold S, Suchman AL. (4)	The role of bioethics and business ethics.	J Gen Intern Med.	1999	Theoretical article	USA
Weber LJ. (9)	Talking on organizational ethics. To do so, ethics committees must first prepare themselves.	Health Prog.	1997	Theoretical article	USA

Table 2. Characterization of articles

Author	Title	Purpose of the article.
Fisher J. (8)	Lessons for business ethics from bioethics.	It emphasizes the possibility of applying the bioethical principles of beneficence, justice and autonomy to resolve conflicts and ethical dilemmas in other business areas.
Hardwig J. (3)	The Stockholder - A lesson for business Ethics from Bioethics?	It argues that bioethics can contribute to business ethics with the knowledge that people have a multiplicity of desires and objectives and that establishing that the sole or main objective of the shareholder is profit is a mistake because part of the shareholders could accept a reduction in profits in exchange of certain patterns of organizational behavior.
Raus K, mortier E, Eeckloo K. (5)	The patient perspective in health care networks.	It argues that it is not advisable to conceive of health organizations as businesses, given the vulnerability of the consumer/patient, and reinforces that one way to ensure organizations focus on patient well-being is to transfer to organizations the duty to meet the bioethical duties of beneficence, non-maleficence, autonomy and justice.
Ells C, Macdonald C. (6)	Implications of organizational ethics to healthcare.	It argues that organizational ethics, for an effective application to the healthcare environment, must pay attention to the special characteristics of organizations by combining tools borrowed from the fields of business ethics and bioethics.
Van Campen LE, Poplazarova T, Therasse DG, Turik M, Biopharmaceutical Bioethics Working Group. (14)	Considerations for applying bioethics norms to a biopharmaceutical industry setting.	It discusses the challenge for organizations to ethically manage the dual mission of profiting and contributing to the common good of society and that when the organization operates in the health sector, bioethical norms must also be applied to business conduct.
Pellegrino ED. (2)	The commodification of medical and health care: the moral consequences of a paradigm shift from a professional to a market ethic.	Highlights the moral consequence of adopting a market ethic in managed health care, emphasizing the difficulties and failures in characterizing health as a commodity.
Eiser AR, Dorr Goold S, Suchman AL (4)	The role of bioethics and business ethics.	It argues that health care is essentially a moral enterprise and that the emergence of health organizations and their care management processes must be evaluated from an ethical and not just an operational perspective.

Weber LJ. (9)	Talking on organizational ethics. To do so, ethics committees must first prepare themselves.	It exposes that ethics committees must be prepared to deal with organizational ethics.
Werhane Patricia H. (13)	Review of The Business Ethics within Bioethics, by Leonard J. Weber.	Conducts a critical analysis of the book "business ethics in healthcare" by author Leonardo Weber, highlighting the evaluation of healthcare from a business perspective and the importance of cost-effective healthcare services.
Kwiatkowski W. (1)	Medicine and Technology. Remarks on the notion of responsibility in technology-assisted health care.	It argues that the moral responsibility of medicine in managed health care is not limited to therapeutic responsibility, extending the responsibility for the fair distribution of health care, and reinforces that the regulation of health services must be influenced not only by technological, economic factors, social but also by philosophical-anthropological postulates.
Pepin JF. (7)	Business ethics and health care: the re-emerging institution-patient relationship.	It emphasizes that one of the main changes in managed health care has brought the resurgence of the patient-institution relationship, but with the loss of the religious foundation existing in Byzantine hospitals, care must be taken with the moral foundation that will serve as the basis for the patient-institution relationship.

Managed care places institutions in a prominent position in the health system, increasing the importance of the patient-institution relationship in the provision of health care and emphasizing the fiduciary responsibility of the institution towards the patient*(7)*.

The need to balance medical activity with the institutions' need for profit and patient autonomy is important in healthcare businesses, and ethics committees should also be prepared to say when healthcare costs outweigh other considerations in the therapeutic decision process*(9)* (Table 2).

The results found were diagrammed in the figure below (Figure 2).

Discussion

When resources are limited, choices must be made about priorities in resource allocation. A society needs a moral vision to guide how resources will be allocated*(16)*.

There are multiple strategies for cost containment and resource management. One strategy is to create a market economy in health care and let market forces develop, distribute, and manage health resources*(16)*.

Managed care represents the introduction of market forces capable of changing from a patient-centered model of medicine to a population-based model and establishing a new level of organization in the provision of health care*(4,16)*.

Managed care is the concept of management, with three distinct types of management being especially important: clinical management, resource management, and administrative management*(17,18)*.

Clinical management in managed care reallocates the concept of individual patient well-being by introducing a view of clinical management that cannot be confined to episodic relationships and supports the development of a more systematic approach to continuity of care*(17)*.

The resource management concept includes reference not only to the individual patient but also to other patients, the infrastructure of healthcare institutions, equipment, human resources, and supplies*(17)*.

Resource management, in addition to the concern with rationing, involves planning for future needs and opportunities, not only saving money but also creating opportunities to assist other patients*(17)*.

Regarding administrative management, two aspects are especially important in managed care: administrative functioning and leadership. Ad-

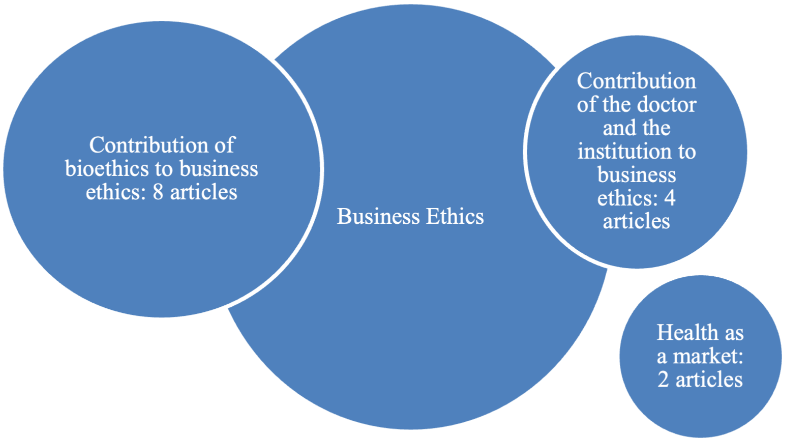

Figure 2. Results diagram

ministrative functions, among other strategies, have performance pay that can inevitably interfere with and promote good patient care*(17)*.

However, the bioethics literature has warned of a wide range of conflicts that managed care introduced into the practice of medicine. Conflicts of economic incentives, conflict with patient and physician autonomy, and conflicts with the fiduciary character of the physician-patient relationship are among the most relevant*(18)*.

Offering financial incentives to physicians to practice economic medicine is a strategy to encourage physicians to keep expenses to a minimum by making them aware of the costs of the services they provide or request from patients*(18)*.

However, if the incentives and use regulations are poorly designed, they can present the risk of profitability arising from abusive practices*(1)*.

Another robust critique of managed care refers to the limitation of medical autonomy, which, through guidelines, reduces the physician's ability to obtain the necessary clinical information, prohibiting procedures and negatively interfering with the physician's and patient's decision-making*(18)*.

These management practices alter the physician-patient relationship and can erode patients' trust in physicians and the healthcare system in general, preventing physicians from acting in the best interests of their patients*(18)*.

If the patient feels that economic rather than clinical criteria define the therapeutic decision, they may develop the feeling of a lost opportunity syndrome*(1)*.

Criticism of managed care triggered the questioning of whether the influence of market rationalities in the health sector is desirable since commercial interests can potentially conflict with other nationalities, for example, the issue of justice*(19)*.

There is a risk that organizations will select patients to maximize profits and close unprofitable services regardless of their social importance*(2)*.

This reflects a broader debate about the moral limits of markets and whether market mechanisms are a means of distributing every kind of product or service. The concern is that the market for some products, such as healthcare, could lead to unfair distribution or erode the product's value*(19)*.

The market logic presents as core values rationality, efficiency, responsiveness to needs and innovation, all to increase profit. Moral deliberation before the act of choosing is a private concern*(19)*.

From the market perspective, care is a negotiable, commodified product. The value of care is fully expressed in monetary terms, with no social significance. Furthermore, the logic of the market considers the provision of care as property*(19)*.

The engine behind the market logic is that organizations continually strive to maximize profit to the satisfaction of shareholders*(19)*.

In contrast, the logic of professionalism is based on the belief that only with training and experience can professionals carry out their specialized activities, and their work cannot be standardized, rationalized, or commodified. For the assistance to be effective and ideal, professionals need a space to control their work*(19)*.

The professional trusts all parties involved; their goal is to meet the patient's needs, not simply what the patient wants or can afford*(19)*.

From the perspective of the professional, health is a fundamental requirement for the fulfillment of human potential. To lack health and need treatment is to be in a diminished state of human existence, which makes the patient vulnerable*(2)*.

Current criticisms of managed care, whether appropriate or not, and the differences between the logic of the market and professionalism deserve an ethical analysis*(18)*.

Managed care is a complex arrangement composed of financial, institutional, and professional components that have been reorganized and redefined in response to historical circumstances. It is ethically important to see managed care in sociological terms. Like any organizational arrangement, one might ask whether the guiding objectives of managed care are ethically sound and whether their organizational structure promotes defensible ethical goals*(18)*.

Within business ethics, the discipline of organizational ethics has been concerned with studying and directing the ethical behavior of healthcare organizations. Simply expressed, organizational ethics seeks to clarify and evaluate the values embedded in the organization's policies and practices, seeking mechanisms to morally establish practices based on acceptable values and policies*(6)*.

The real challenge is to combine business ethics and bioethics to provide credible, ethical guidance*(17)*.

The overlap of business ethics and bioethics is a strategy to balance conflicts of interest. Business ethics often addresses the principle of justice in the balance between individual interests and group interests. However, the focus of bioethics on the principle of beneficence and autonomy needs to be extrapolated from the doctor-patient relationship to also compose the institution-patient relationship. In managed care and health organizations, benevolence should not be limited to the actions of those who act on its behalf, as they are moral agents who have beneficent duties like any other citizen, but the institution itself should establish beneficence as a guiding principle of its organizational structure*(8)*.

Therefore, to achieve the objective of placing the patient at the center of attention in managed care, the regulation of resources must be influenced by economic and philosophical and anthropological factors*(1)*.

Managed care and healthcare organizations must be willing to reduce profit to ensure the protection of patient's health, physicians must accept to harmonize their professional conduct for the benefit of moderate profits and the financial sustainability of the system, and patients must give up some aspects of their autonomy that may burden the managed care. The overlap of the knowledge domains of business ethics and bioethics has the potential to build a code of conduct that helps in the search for this necessary balance for the survival and evolution of managed health care*(4)*.

The growing interest in overlapping these disciplines is evident from the observation that all articles selected for this scoping review found in the literature were published from 1997 onwards*(1-9,13,14)*.

Publications were made by journals of medical ethics, business ethics, bioethics and philosophy, internal medicine and business management, showing that the perception of the need for the intersection of bioethics and business ethics is being perceived by various sectors of society*(1-9,13,14)*.

An important aspect of the results found is that most of the authors are Americans, a fact explained by the health system model used by the United States of America, which may indicate that the authors perceive weaknesses and distortions in the health system model adopted*(2-4,7,9,13,14)*.

However, despite the literature reinforcing the importance of overlapping the disciplines of bioethics and business ethics in managed care, the articles do not explore how to achieve this objective; there is a predominance of theoretical articles.

The results achieved by this scoping review are limited by not presenting research articles capable of demonstrating the best ways to include bioethics in the agenda of managers of health organizations and by not dimensioning the positive and negative consequences of the overlap of the two disciplines. In addition, the results are limited because most authors are from the USA which can be considered a bias.

This evidence gap, demonstrated in this scoping review, should serve as a stimulus and guidance so that future research can prove the best mechanisms to effect the fusion of the principles of bioethics and business ethics and thus contribute to the consolidation of managed care of health.

Conclusion

In recent decades, the literature has produced knowledge about the insufficiency of business ethics in responding to patient's wishes and balancing this complex conflict of interest that arose from the health economy and its characterization as a commodity.

Despite the perception of several authors that business ethics and bioethics need to come together to find a solution to the dilemmas that affect managed care and organizations that act as health businesses, few articles delve into developing mechanisms to solve these ethical dilemmas.

This scoping review aims to examine the existing literature on the topic of business ethics and bioethics in healthcare organizations and managed care, and it is concluded that several authors see the overlapping of the knowledge of business ethics and bioethics as a strategy that can solve the dilemmas and conflicts existing in the health system.

Despite this, there are still few studies addressing the intersection of these two disciplines, which limits the conclusion of the best way to condense the knowledge of business ethics and bioethics in a way that can serve as an analytical framework capable of being widely used in organizations and managed health care.

This article demonstrates the importance of the moral and ethical aspects in managed care and health organizations and the need to advance in this line of research.

Declarations

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HOW SHOULD WE TREAT PET ROBOTS?

Wei Li[1], Zhonghua Zhang[2], Shuang Li[3], Wei Wu[4]

Abstract: Pet robots can overcome the shortcomings of pets and accompany people instead of pets. There are also some ethical concerns about pet robots, including that pet robots will cause people to deceive themselves, that people's attachment to pet robots will make people miserable, that people will change their original value hierarchy, and that people will behave unethically toward pet robots. To make pet robots better integrate into society, people must treat them correctly, such as enjoying the happiness brought by pet robots, strengthening the independent training of robot pets, not easily changing the value hierarchy of self and being forbidden to behave immorally towards pet robots.

Keywords: pet robot, self-deception, attachment, value hierarchy, unethical behavior

¿Cómo debemos tratar a los robots mascota?

Resumen: Los robots mascota pueden resolver algunas limitaciones asociadas con las mascotas tradicionales y brindar compañía como una alternativa. Sin embargo, también surgen preocupaciones éticas respecto a su uso. Entre ellas se encuentran: el riesgo que las personas se engañen a sí mismas, el vínculo emocional hacia los robots mascota podría llevar a sentimientos de desdicha, una posible alteración de la jerarquía de valores personales y el temor a conductas poco éticas hacia estos dispositivos. Para facilitar una integración adecuada de los robots mascota en la sociedad, es importante adoptarlos con una perspectiva responsable: aprovechar los beneficios de felicidad que aportan, fomentar el desarrollo de habilidades de autogestión en estos dispositivos, mantener sólidos los valores personales sin alterarlos fácilmente y evitar cualquier comportamiento inmoral hacia ellos.

Palabras clave: robot mascota, autoengaño, apego, jerarquía de valores, comportamiento poco ético

Como devemos tratar os robôs de estimação?

Resumo: Robôs de estimação podem superar as deficiências dos animais de estimação e acompanhar as pessoas ao invés dos animais de estimação. Existem também algumas preocupações sobre os robôs de estimação, incluindo se eles farão com que as pessoas se enganem, se o apego das pessoas a eles farão as pessoas infelizes, se as pessoas mudarão sua hierarquia de valores originais, e se as pessoas se comportarão de forma anti-ética em relação aos robôs de estimação. Para que os robôs de estimação se integrem melhor à sociedade, as pessoas necessitam tratá-los corretamente, como desfrutar da felicidade trazida por eles, fortalecer o treinamento independente dos robôs de estimação, não alterar facilmente a hierarquia de valores de si mesmos e serem proibidos de se comportar imoralmente em relação aos robôs de estimação.

Palavras chave: robôs de estimação, auto-engano, apego, hierarquia de valores, comportamento anti-ético

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1. Introduction

Pets have been closely related to humans since ancient times. For most people, pets have exceeded the scope of ordinary animals, and gradually become family members, bringing joy and happiness to people. Humans embrace, pat, and play with their pets, and pets reciprocate with unconditional love. However, although pets bring us a lot of happiness and company, their shortcomings, such as parasites on the body, damaging furniture and other behaviors, often bring trouble to people. With the continuous progress of technology, more and more people have begun to use artificial intelligence (AI) and robotics to meet their needs. In the field of pets, pet robots have attracted more and more attention and favor in recent years. Compared with pets, pet robots do not need to feed, will not suffer from parasites, and will not have harmful behaviors such as biting people. At present, many pet robots have accompanied humans, including the robot seal Paro, the robot dog AIBO, the robot cat NeCoRo and the robot dinosaur Pleo*(1)*. In China, CyberDog, a bionic four-legged robot developed by Xiaomi, has also begun to enter people's lives. Although pet robots can bring people a lot of benefits, their emergence has also caused some ethical concerns. This article clarifies and analyzes these ethical concerns, and explores how people should treat pet robots from an ethical perspective.

2. Human and pet robots

At present, for human beings, animals are not only a tool to achieve people's goals. On the contrary, some animals, such as dogs, cats, parrots, turtles, and even hedgehogs, lizards, and raccoons, have been regarded as partners or family members. When we walk on the road, we often see the scene of owners walking with their pet dogs or children playing with pet cats. It can be said that pets have penetrated human society and changed people's lives imperceptibly. For example, a foreign prison has implemented a policy that the prison rewards prisoners with a cat as a pet for good behavior in the hope that the cat will help prisoners reform. In addition, pets can accompany the elderly to keep them away from loneliness, soothing people's emotions when people worry. Although pets can bring many benefits to people, they also have some unbearable shortcomings, such as pet dogs will attack humans, pet cats will catch furniture, pet birds will bother their neighbors in the early morning.

Of course, for those who love pets, even if there are some shortcomings with their pets, they can accept it. But for those who do not have a clear attitude towards pets, other people's pets will disturb their normal lives. For example, people walking on the road will be afraid of pet dogs suddenly attacking them, people do not like to be woken by the neighbor's dog barking and so on. At the same time, people will also worry that other people's pets will hurt their own pets.

In daily life, people are trying to make their pets as little trouble as possible, such as walking the dog on a leash and wearing a muzzle to prevent people from biting, and keeping the doors and windows of the house closed to prevent cats from running into other people's house. However, some pet owners may not be aware of this or lack the necessary knowledge and skills to properly manage their pets, which can easily lead to pet-human or pet-pet conflict.

Faced with the above situation, people have developed pet robots to replace pets. A pet robot is a social robot that has the appearance and behavior of a pet or companion animal*(2)*. This has two meanings. First, the appearance of pet robots is similar to real pets, including but not limited to dogs, cats, birds, turtles, and even creatures that do not exist in real life, such as dinosaurs; Second, in terms of behavioral activities, the pet robot is similar to the real pet, including but not limited to sleeping, running, coquetry to the owner like real pets. At present, pet robots can perform some of the interactions that real pets do with their owners, such as when Danijar Hafner and colleagues at the University of California, Berkeley, successfully trained robotic dogs to pick up a ball and move it from tray to tray*(3)*. In addition, pet robots can also play a certain role in psychological therapy. Dorothée François and others have shown that children with autism can develop or express their reasoning about mental states and social relationships, as well as learn basic causal responses while playing with pet robots*(4)*.

Not only that, pet robots have more advantages than real pets, for example, pet robot dogs can have real-time conversations with their owners, rather than real pet dogs that can only emit "barking" to their owners to express their emotions and wishes. For those with disabilities (such as the visually impaired), pet robot dogs equipped with advanced cameras, voice systems and sensors can more effectively let their owners know what is happening on the road to avoid the dangers caused by complex road environments. In the future, with the progress of science and technology and the rapid development of generative artificial intelligence, pet robots will continue to evolve and their behaviors will be more diverse. ChatGPT, for example, will be implanted into the pet robots*(5)*, which not only makes the pet robots all-knowing but also enables people to experience more fun interacting with the pet robots.

In addition to the same characteristics as real pets, pet robots can surpass real pets and make up for the shortcomings of real pets to a certain extent, such as preventing people from walking dogs and getting bitten*(6)*. People's money invested in real pets is relatively large, involving the purchase, feeding, shearing, treatment of diseases, etc. Pet robots will greatly reduce the relevant expenses. These advantages of pet robots have become an important reason for people to adopt and accept them. After all, society's tolerance for pets depends not only on whether pets can bring happiness to their owners but also on whether pets violate the interests of others. And these two points, pet robots can be well satisfied.

In addition to money, some pets (such as pet dogs) need the company and attention of their owners, and people may worry about whether they have the energy and time to raise such pets. Especially for those who like a pet, but because of reasons (such as allergies to animal hair) cannot keep a pet, not being able to raise a pet may be a big regret. Pet robots can imitate the behavior of real pets, and with the progress of technology, pet robots will be more and more like real pets, so they can bring people the same fun as real pets. However, it is worth noting that even if the pet robot has one benefit or another, we cannot ignore the moral problems it brings to people.

3. People are concerned about the ethics of pet robots

As mentioned above, pet robots can bring people joy and replace pets to some extent. In addition, for humans, pet robots and general robots also have a big difference. Japanese scholar Tatsuya Nomura has shown through research that the task attributes of pet robots are different from those of sweeping robots, the latter is a specific task, while the former is an abstract task, that is, interaction with humans*(7)*. If you view pet robots from a utilitarian perspective, their existence is undoubtedly good, because pet robots will bring owners much more happiness than pain. However, as with other emerging technologies, the emergence of pet robots has raised some ethical concerns, focusing on the following areas:

The first ethical concern is that pet robots will cause people to deceive themselves. This self-deception violates people's obligation to accurately understand the world. Robert Sparrow discusses the morality of pet robot dogs leading humans to self-deception in his paper. For most people, pet robots can be accepted by society, after all, they can make people feel happy. But for Sparrow, the design and manufacturing of pet robots is unethical. The reason he gives is that if people want to benefit a lot from having robot pets, they must systematically deceive themselves. Indulging in such sentimentality violates the (tenuous) responsibility we must accurately understand the world*(8)*.

Sparrow does not deny the benefits of pet robots. For example, he admits that pet robots can allow the elderly to avoid loneliness and comfort the elderly. However, he still insists that society should not have pet robots. In the process of contacting the elderly with pet robots, the elderly will unconsciously consider the pet robot as a real animal, not a robot. This also means that the prerequisite for people to get the happiness brought by pet robots is that they must recognize pet robots as living animals in reality. For example, the happiness obtained by the elderly in interacting with pet robot dogs is based on the elderly treating pet robots as real dogs. Sparrow, then, found that if people's happiness with a pet robot is based on an inability to see things as they are, it means that people must deceive themselves, and this deception is based on sentimentality. When people indulge in such emotions, they end up in conflict with their feeble obligation to understand the world accurately. Therefore, Sparrow believes that the biggest problem that pet robots bring to people is that they will make humans violate their obligations, which is unethical.

The second ethical concern is that pet robots will make people have a strong attachment emotion, which will bring pain to people. Pet robots will be widely used in society, they can be used as children's playmates, can accompany the elderly, and can be used as guide dogs for the visually impaired. Therefore, like real pets, people will gradually have feelings like friends or relatives for pet robots, and this feeling will make people more and more attached to pet robots. Then, when this attachment is broken, people will fall into difficulties such as attachment disorder and be surrounded by pain.

Rhonda Martens has found that the disconnect between people's beliefs and behaviors during contact with pet robots can lead to distressing cognitive dissonance over time. If this pain occurs after the person has developed a strong attachment to the pet robot, then taking away the pet robot is replacing one pain with another*(9)*. When people come into contact with a pet robot, the pet robot stimulates people's strong emotions which makes people no longer regard the pet robot as a robot but as something important to them. However, there is a view that the emotions humans give robots are mostly "wishful thinking" and asymmetric*(10)*. What this paper argues, however, is that the iterative evolution of pet robots will enable them to adapt and learn how to interact with humans throughout their lives, and incorporate these experiences into their understanding of themselves, humans, and their relationships with humans. This also means that pet robots are bound to express emotions to us and respond to human care in the same way that real pets do. Therefore, when people become attached to pet robots, the departure of pet robots will make people feel sad.

The third ethical concern is that people often change their original value hierarchy after long-term contact with pet robots. Eva Weber-Guskar discovered this problem and illustrated it with the example of Karen and the robot dinosaur. In this example, Karen lived with the robot dinosaurs for many years, and they developed a strong bond with each other. As Karen sat in the doorway, a child came along to play with the robot dinosaur. But a car suddenly hurtled towards the children and the robot dinosaur, and Karen had to decide whether to save the robot or the child. And at last, she chose to save the robot dinosaur rather than the child. The usual hierarchy of values holds that human life should be the most important relative to other lives. However, in this example, we can find that after people establish a deep relationship with a pet robot, people may choose to save the life of the pet robot and give up the life of human beings, which changes the value hierarchy that people originally held.

Guskar insists that there are obvious differences between humans and robots when people have a relationship with robots. On the one hand, humans are living, sentient beings, and on the other hand, robots are functioning machines and software. Therefore, there is no good reason to change the hierarchy of people's values, namely that saving lives is more valuable than preventing things from being destroyed, and that the responsibility to save human (or animal) lives is more important than keeping things from being destroyed*(11)*. Although Guskar is against putting the life of a pet robot above the life of a human, we should also see through this example that people have more affection for the pet robot than other people. When we are faced with a choice between human life and non-physical objects (such as robots), it would be unacceptable to favor the lives of robots over the lives of humans. For the topic of whether pet robots have life, there is still a certain debate. However, as can be seen from this example, people tend to change their general value hierarchy during contact with pet robots.

The fourth ethical concern is that people may do unethical behavior to pet robots, and even hurt pet robots. For pet robot owners, their pet robots are like their own family. Therefore, the owner should not inflict harm on the pet robot, and other people also can not hurt his pet robot. But the reality is not so, we often see in the news that the owners of pets mistreat their pets and do other immoral behaviors. As is the case with living pets, pet robots may suffer the same fate. Research has shown that people often take an "intentional stance" (as opposed to a mechanical stance) when interacting with robots, and that people's prior experiences, beliefs, and expectations of robotic systems can be further moderated up or down*(12)*. This also means that there is a high probability that people will behave immorally towards non-living beings.

James Yeates and others believe that the reason why pet owners behave immorally towards their pets is that the pet owner considers himself to be in a power relationship with the pet, which is determined by the pet owner's ownership of the pet. For example, human actions can cause or prevent pets from experiencing pain or pleasure, obstruct their desires, limit their freedom, or activate, end, or prolong their lives*(13)*. Then, if all people hold on to that idea, they will also behave unethically towards pet robots, such as kicking them or abandoning them. On the other hand, those who are not interested in or disgusted by pet robots, have not established an intimate relationship with pet robots, so pet robots may not be alive in their eyes. Therefore, they believe that even if unethical behavior is imposed on a pet robot, it will not cause harm. This view is supported by the findings of Anne M. Sinatra and others, who find that the addition of features similar to living beings does not necessarily mean that the robot will be considered living beings*(14)*.

Through the discussion of the above four kinds of ethical concerns about pet robots, it can be found that the implementation of these ethical concerns is human. Therefore, if humans want to reduce ethical concerns about pet robots, humans need to be clear about how to treat pet robots properly.

4. The way people treat pet robots correctly

In the above, we have listed four ethical concerns that pet robots will bring to humans. To make pet robots better integrated into society and better help humans, we must discuss how people should treat pet robots.

Firstly, people should correctly understand the behavior of self-deception and feel the happiness brought by pet robots. As today's robots become increasingly socially autonomous, anthropomorphic, and concrete, it seems that children and adults see them as having lives, mental states, social, and moral values*(15)*. This also means that in the process of contact with pet robots, people will regard them as a part of their lives and the sustenance of the spiritual world. However, Robert Sparrow also believes that pet robots will allow people to deceive themselves, which will conflict with our obligation to understand the world correctly. What this article is arguing is that people tend to give "life" to things they have attached affection to, and this tendency is not only seen in pet robots but also in other things, such as virtual humans. Therefore, according to Sparrow, if people have strong feelings for something, they will deceive themselves in many aspects of life because it is not consistent with the things or objects projected in their minds, which is unacceptable.

There is no denying that people do have the possibility of self-deception in the process of contact with pet robots. Tamar Szabó Gendler, a professor of philosophy at Yale University, argues that beliefs respond to things as they are not just about tendencies or how things look. The actions produced by beliefs are generated by a mental state that is related to all that is seen as evidence and is modified by reason and norms*(16)*. This means that in the process of getting along with pet robots, people will correct the objective fact that pet robots are not alive. In this process, the inconsistency between beliefs and facts will lead people to self-deception. However, what we need to be more clear is that the owners of pet robots must know that the pet robots accompanying them are not living objects but robots that rely on electric energy. Even if we ask pet robot owners if their pet robot is alive, even if they say yes, it doesn't mean that people can't correctly understand whether their pet robot is alive.

For most people, when they get along with pet robots, they give their love to pet robots, and pet robots respond with love, and their getting along makes both of them happier. So in this sense, whether pet robots make people go to self-deception, or whether they violate people's obligation to know the world, these are no longer important compared to the happiness brought by pet robots. Russell Blackford offers a more optimistic view of the self-deception caused by pet robots, arguing that:

> What seems clear, however, is that we should cut each other, and ourselves, some intellectual slack when it comes to familiar, relatively benign, kinds of self-indulgence in forming beliefs about the facts of life. I expect that we can tolerate a great deal: people's over-optimism and overly favorable self-perceptions; their comforting interpretations of the characteristics and motives of loved ones and mammalian pets*(17)*.

Therefore, when pet robot owners face the self-deception that pet robots may cause, it is better to let themselves relax and enjoy the happiness brought by pet robots.

Secondly, people should treat the attachment feelings of pet robots correctly and strengthen the independence training of pet robots. For owners, the relationship between them and their pet robot is just like the relationship between pet owners and their pets. For why pet robots can communicate with people, Daniel H Grollman believes that pet robots are qualified for certain social roles, and need to develop or have the following three abilities: The ability to perceive and interpret human social signals, to send signals that untrained people can understand, and to change their behavior in response to interactions with humans*(18)*. Grollman's core idea is that pet robots can understand what people say and do, and can interact with people through their own words and actions. Therefore, we can believe that the deep feelings between pet robots and people are gradually established through the continuous and effective interaction of both sides. This is one of the important reasons why people are in grief when they are separated from their pet robots.

We all have this experience in our daily lives, when we lose a close friend or family member, we will fall into deep grief. For us, they are the people closest to us, and our love and affection for each other bring us a lot of happiness. Similarly, for pet robots, our love for pet robots brings them a lot of happiness, and they also have a great dependence on us. We need to understand that, in addition to dependent motives, the behavior of these pets toward their caregivers also depends on their dependence on us, on educational and normative influences which need to be carefully examined*(19)*. This means that when we treat the pet robots better, pet robots will reciprocate with the same attitude and behavior. So, after we have formed an attachment to our pet robots, how should we deal with the sadness of losing our pet robots?

The first thing we should make clear is that we should not just treat pet robots as machines that can act autonomously but should treat them as partners or family members in the process of getting along with pet robots. At the same time, we should treat them with good intentions, so that we can avoid falling into self-blame when we part with pet robots. When we are separated from pet robots, just like humans and real pets, although the separation is sad, the good past with pet robots is real. However, to prevent pets from becoming too attached to their owners in the future, we should strengthen the independence training of pet robots. For example, pet robots could be left to pursue their interests, rather than just spending time with their owners; Give pet robots alone time and teach them to cope well with loneliness without owners. These behaviors do not make pet robots less loving to people, and at the same time, pet robots do not feel lonely and abandoned by their owners when people go out. Cultivating the confidence and independence of pet robots can not only allow pet robots to enjoy their time without owners but also enable people to live well without pet robots and reduce the pain of people attached to pet robots.

Thirdly, even if people have deep feelings for pet robots, they should not easily change their value hierarchy. The example of Karen and the robot dinosaur has demonstrated that humans and pet robots can develop deep feelings for each other, which can lead to a tendency to regard the life of a pet robot as more important than human life. If we use ethics to argue that the life of a pet robot should not be more important than that of a human being, it's a good way to borrow Kant's idea. Kant, as the representative of deontology, believed that " in all creation, all that man desires and can control are used only as means; Man alone, and with him every rational creation, is the goal itself*(20)*." Treating people merely as a means to the goal undermines human dignity, and giving up a human life as a means to save the life of a pet is also damaging human dignity. Therefore, it is immoral to give up saving human lives to save the lives of pet robots, we cannot save the lives of pet robots at the expense of human lives.

The ultimate goal of scientific and technological progress should be to bring people a better life. If we view technology in this way, we cannot destroy the better life for technology. When people save the lives of pet robots by giving up human lives, they are putting technology products above the good life. But if a man loses his life, then for himself, his good life cannot be realized. Pet robots, as a type of robot, should abide by the relevant moral rules of robots. Asimov's first law states that a robot may not harm a human being or cause a human to be harmed by inaction. So, if we ask the robot dinosaur to replace Karen and make a choice between human life and its own, we can trust that the robot dinosaur will want to sacrifice its own life to save the life of that child. So, the owners of pet robots should respect the opinions of pet robots to save the lives of children.

In addition, what we can't ignore is that the lives of pet robots are very different from human life. The life of a human being is only once, but the life of a pet robot can be infinite. People cannot be revived after death, but pet robots can be revived by various means after death. After the death or destruction of a pet robot, the pet robot owner can purchase a pet robot of the same model and transfer the memory of the original pet robot that has been digitally preserved to the new pet robot. Since then, the original pet robot will be revived in another way. Regardless of whether pet robots have lives or not, people should not put human life under the lives of pet robots, especially at the cost of giving up human life to save a pet robot's life. In short, for people who establish deep feelings with pet robots and their value hierarchy has changed, people should first respect the value of human life, which is the premise of respecting others, self and pet robots.

Finally, people should start from an anthropomorphic perspective and prohibit unethical behavior toward pet robots. It is considered immoral to harm pets. But by replacing pets with pet robots, given the general perception that pet robots are inanimate, people may behave in ways that harm pet robots. What this article argues, then, is that people should not behave immorally towards pet robots, even if they are regarded as inanimate objects. Research by University of Canterbury academic Christoph Bartneck and others has shown that abusing robots is just as immoral as abusing humans. While this may not automatically mean that robots are equal to humans in all respects and all situations, it does at least suggest that bullying behavior is considered immoral, no matter who the victim is*(21)*. We can assume that animals suffer from being kept in a confined environment because we find it unacceptable when we assume that we are in such an environment. Then we should also anthropomorphize how animals feel in other situations*(22)*. Similarly, if we were to become pet robots, we would not want others to behave unethically towards us.

From the perspective of Kant, our behavior toward nonhumans reflects our morality. If we treat animals in an inhumane way, we become inhumane people. Kate Darling of the Massachusetts Institute of Technology has logically extended Kant's view that pets should not be mistreated to robots. Kate Darling points out that giving robots protection may reinforce human behavior of our own, which we usually think is morally right, or at least makes our cohabitation more enjoyable. It can also prevent the desensitization of humans to real creatures and protect our empathy for one another. Admittedly, this reason may be at odds with most people's current understanding of animal laws, but it seems to make sense in analogy to Kant's reasoning*(23)*. Kate Darling makes three points in her argument. First, practicing good behavior toward pet robots will reinforce good behavior in us; second, practicing good behavior toward pets can effectively promote a pleasant experience in the process of contact between humans and pet robots. Third, practicing good behavior toward pet robots can increase human empathy. It can be found that our behavior choices for pet robots can not only bring good feelings to pet robots but also make humans become better selves from the perspective of humans themselves.

On the contrary, inflicting violence on a pet robot will not only harm the pet robot (whether it is physical or emotional damage) but also make the perpetrator an immoral person. This view is consistent with Virtue Ethics. Our good behavior makes us good people, so to become good people, we should not practice immoral behavior toward pet robots but should practice good behavior toward pet robots. As Deborah G. Johnson of the University of Virginia has argued, cruelty to humanoid robots desensitizes us to human cruelty, or cruelty to humanoid robots increases the likelihood that we will be cruel to each other*(24)*. Therefore, people should avoid unethical behaviors when treating pet robots, which are not limited to abusing, and discarding robot pets, but also include not charging pet robots and not updating the robots' system.

To sum up, we need to treat pet robots correctly to reduce people's moral concerns about pet robots. Only in this way can we let pet robots truly integrate into people's lives and expect them to bring more joy and happiness to humans like real pets.

5. Conclusion

As pet robots gradually enter people's lives, they will exist as human partners or family members like pets. Even if pet robots can't replace real pets, that doesn't mean pet robots can't have some of the functions of real pets. Children, they need cute and interesting pet robots to play with them; young people, need obedient and smart pet robots to relax them. For the elderly, they need gentle and understanding pet robots to keep them from being lonely. It is conceivable that with the continuous development of artificial intelligence and robotics, future pet robots will be able to interact with people in a more complex way. In the process of interaction between people and pet robots, both sides will have a deep attachment, which means that pet robots can provide the same emotional value to people as pets. The research and development of pet robots requires the joint efforts of people related to robotics, artificial intelligence, ethics, psychology, biology, anthropology and other disciplines, which is not an easy job, but it is a necessary work. The high cost of currently available pet robots leads to prohibitive inequalities*(25)*, so we hope that well-functioning, affordable pet robots will be produced as soon as possible. This involves not only the functional issues of pet robots but also the ethical issues of pet robots. We want pet robots to be able to bond with people like real pets, but that doesn't mean they have to replace real pets. On the contrary, pet robots can serve as an important supplement to real pets, allowing those who cannot keep real pets for various reasons to experience the joy of keeping pets.

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IN MEMORIAM JORGE JOSÉ FERRER NEGRÓN SJ (PUERTO RICO, 14/09/1951 - 21/09/2024)

Javier Rivas Flores[1]

Jorge Ferrer Negrón fue un jesuita comprometido, tanto en el mundo intelectual, como profesor de bioética, como en el mundo social desde su condición de sacerdote jesuita.

Tuve el honor de colaborar y trabajar con el profesor Ferrer cuando fue director de la Cátedra de Bioética de la Universidad Pontificia de Comillas, de la que era profesor, que tuvo que asumir tras el fallecimiento de su creador y primer director, el P. Javier Gafo Fernández, SJ. Su generosidad y entrega al mundo de la bioética le llevó a trasladarse desde Puerto Rico a Madrid para hacerse cargo de todas las actividades de la cátedra, siempre muy activa en cuanto a la docencia, que se inició en el año 1997; también de los seminarios anuales que organiza tanto para el análisis de los dilemas éticos de la medicina actual, como los dedicados al mundo de la discapacidad, organizados con la Fundación PROMI.

En la dirección de la cátedra estuvo entre 2001 y 2002, y regresó luego a su Puerto Rico natal donde, a la sazón, tenía su plaza de catedrático en el Departamento de Humanidades de la Universidad de Puerto Rico en Mayagüez. Durante esos dos años dejó clara constancia de su valor como persona, en primer lugar, y como profesor. En estos años se crea un consejo de cátedra con la función de ayudar y asesorar para llevar la bioética al punto social que le corresponde. Es en esta época cuando más cercanía y, por tanto, conocimiento tuve de su persona, al ser miembro del consejo asesor. Aunque le conocía en su faceta de profesor, en estos dos años supe de una persona que irradiaba alegría y sentido del humor, extremadamente responsable, con una mirada siempre puesta en los temas sociales y con una consideración preferente por los más desfavorecidos, los que, en palabras del Papa Francisco están en la periferia de la vida. Estos dos años de contacto me dejaron una huella profunda traducida en amistad que se mantuvo hasta su fallecimiento.

Es de resaltar, como ya han manifestado otras personas, su gran talla intelectual, la sabiduría, la solidaridad, el buen hacer, el buen humor, la alegría de vivir, la amistad y la bondad, que siempre ha sido su nota identitaria, con su inmensa sonrisa que demostraba su complicidad con las personas con las que se relacionaba.

En España, la Asociación de Bioética Fundamental y Clínica es una de las más activas y Jorge Ferrer se identificó con la misma, no en vano bastantes de sus socios han sido alumnos o compañeros de viaje en el mundo de la bioética. Esto propició que, en el periodo en el que Jorge fue presidente de la Federación Latinoamericana y del Caribe de Instituciones de Bioética (FELAIBE) se llegara a un acuerdo de colaboración entre ambas instituciones.

En el plano académico hay que destacar su brillante trayectoria. Se graduó en 1972 en la Universidad de Santo Tomás de Houston (Texas) (Bachelor of Arts) y un año después en la Universidad de Notre Dame (Indiana), estudió su bachiller en Teología y licencia en Teología en la Universidad Gregoriana (Roma) entre 1973-1977.

Desde su ordenación sacerdotal en 1977 unió a su labor docente su dedicación pastoral, ingresando en la Compañía de Jesús en 1983, donde, ya desde el noviciado, mantuvo su actividad como profesor visitante de Teología Pastoral en el Seminario San Vicente de Paúl de Boynton Beach (Florida), y posteriormente profesor en centros de los jesuitas en San Juan.

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Entre 1988 y 1991 prepara su tesis doctoral bajo la dirección del Prof. Javier Gafo en la Universidad Pontificia Comillas, que defiende en 1992 sobre *El virus de inmunodeficiencia humana (VIH): su problemática teológico-moral*.

A su vuelta a Puerto Rico inicia su magisterio en el Centro de Estudios Dominicanos en Teología, pasando posteriormente como profesor al Centro de Humanidades Biomédicas de la Facultad de Medicina de la Universidad Central del Caribe en Bayamón. De 1996 a 2001 fue profesor de Teología Moral en el Seminario Mayor de San Juan (Puerto Rico), año en el que es requerido para hacerse cargo de la Cátedra de Bioética de la Universidad Pontificia Comillas en Madrid, en la difícil tarea de sustituir a querido maestro Javier Gafo, reto que afrontó con enorme entusiasmo, a pesar de la importante carga emocional que conllevaba. A su regreso a su patria en 2003 pasa a ser docente de la Universidad de Puerto Rico en Mayagüez y es nombrado director del Instituto Hostos de Bioética de la Universidad de Puerto Rico.

Compaginando esta labor docente con la pastoral, estuvo destinado bien como párroco o coadjutor en diversas parroquias. Ha sido fundador y director de la Escuela de Teología a instancias de la Conferencia Episcopal de Puerto Rico.

En reconocimiento a su altura científica y humana ha sido miembro de la Comisión Teológica Internacional y académico de número de la Pontificia Academia para la Vida de la Santa Sede.

Ha escrito varios libros de bioética, pero hay dos que me parecen fundamentales para los que se inician en el estudio de esta disciplina: *Para fundamentar la bioética. Teorías y paradigmas teóricos en la bioética* contemporánea, y *Bioética: el pluralismo de la fundamentación*, ambos editados en la Universidad de Comillas. Igualmente, ha publicado un buen número de artículos con muy acertadas reflexiones sobre los temas más actuales y de mayor controversia en el mundo de la bioética, lo que, como a otros jesuitas dedicados a la bioética, le puso en el punto de mira de algunas estancias vaticanas.

Destaco su empeño de tender puentes entre la bioética y la moral católica, haciendo carne del lema de Potter, que la biótica es un puente, algo que une y no que separa. Su profunda fe y pertenencia a la Iglesia han marcado su vida, pero no de manera dogmática sino de forma constructiva.

Los que compartimos algunos momentos de su vida y también de su fe, sabemos que está felizmente en la presencia del Padre y que desde allí seguirá trabajando por un mundo más humano y al mismo tiempo más lleno de Dios.

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SEMINARIO INTERNACIONAL “NEUROCIENCIAS, INTELIGENCIA ARTIFICIAL Y DERECHO” UNIVERSIDAD AUTÓNOMA DE QUERÉTARO 28-30 AGOSTO DE 2024

Jesús Armando Martínez Gómez[1]

Se realizó el Seminario Internacional “Neurociencias, Inteligencia Artificial y Derecho, organizado por la Cátedra de Investigación homónima de la Facultad de Derecho de la Universidad Autónoma de Querétaro (UAQ), México, con el objetivo de promover el diálogo crítico en torno a los avances de las neurociencias y la Inteligencia Artificial (IA) en su relación con el Derecho, para contribuir a generar conciencia acerca de la necesidad de la regulación de su explotación y uso.

El seminario fue inaugurado el día 28 de agosto por destacadas autoridades académicas de la facultad de Derecho de la UAQ, como el Dr. Edgar Pérez González, director de la Facultad, la Dra. Karla Elizabeth Mariscal Ureta, jefa de Investigación y Posgrado, el Dr. Jesús Armando Martínez Gómez, coordinador del Centro de Investigaciones y responsable de la Cátedra de Investigación en Neurociencia, Inteligencia Artificial y Derecho, y el Dr. Víctor Manuel Castaño Meneses, corresponsable de ésta, quienes enfatizaron en la importancia del evento para contribuir a la toma de conciencia sobre la necesidad de regular el uso de estas tecnologías emergentes en beneficio de la sociedad. La conferencia magistral de apertura, a cargo del Dr. Francisco León Correa, de la Universidad Central de Chile, abordó los desafíos de la IA para la persona y su integridad, sentando las bases para los temas y discusiones posteriores.

Durante los tres días del evento se impartieron cuatro conferencias magistrales y se realizaron siete mesas temáticas, que contaron con la moderación de reconocidos académicos, lo que permitió cubrir una amplia gama de temas, desde la ética y el humanismo en la programación y uso de la Inteligencia Artificial y las neurociencias, hasta la implicación de la IA y las neurotecnologías en la salud y las decisiones médicas, la educación, la cohesión social y los derechos humanos. En total, participaron 56 ponentes de instituciones de México, España, Chile, Colombia, Cuba e Italia, quienes compartieron investigaciones y reflexiones acerca de los beneficios y retos derivados del uso de estas tecnologías para la sociedad.

El primer día los panelistas de la Mesa 1 exploraron los dilemas éticos más importantes en la regulación de la IA, con ponencias que subrayaron la necesidad de desarrollar una normativa ética como antesala y referente para normación jurídica. En la Mesa 2 se discutió el concepto de humanismo en la era de la IA, analizándose cómo las neurotecnologías afectan los fundamentos ontológicos y axiológicos de la vida humana. La Mesa 3 se centró en el análisis de las cuestiones éticas derivadas del uso de la Inteligencia Artificial y las neurotecnologías en el diagnóstico, tratamiento y prevención de enfermedades.

El segundo día del seminario inició con la conferencia magistral del Dr. Matthias Etienne Alphonse Nebel, director del Instituto Promotor del Bien Común de la Universidad Popular Autónoma del Estado de Puebla, México, quien exploró la brecha entre algoritmos y mente humana, un tema que despertó gran interés, promoviendo el debate entre los asistentes. Asimismo, en la Mesa 4 se analizaron los avances en materia de regulación legal de la IA en el contexto europeo, resaltándose la necesidad de una unificación normativa para regular esta tecnología a nivel global. La mesa 5 abordó la cohesión

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social y la seguridad, explorando los desafíos éticos del uso de las neurociencias en la labor criminológica y política, sus fundamentales retos y perspectivas. En la sesión de este día también se impartió la tercera conferencia magistral del Seminario, a cargo de la Dra. Beatriz Eugenia Campillo Vélez, de la Universidad Pontificia Bolivariana de Colombia, quien abordó el tema de los desafíos que representa para la democracia la utilización de algoritmos para la toma de decisiones políticas.

El tercer día, la Dra. Carolina Santacruz-Pérez, Science Officer, Latin American and Caribbean Region, ofreció una conferencia magistral sobre la inteligencia artificial y la brecha de género, un tema de gran relevancia en la actualidad. Finalmente, la Mesa 7 analizó la relación entre neurociencias, neurotecnologías y derechos humanos, valorando la incidencia de estas tecnologías en la reconfiguración del contenido y alcance de los derechos humanos, así como sus retos y desafíos para la protección de los derechos humanos.

En resumen, el seminario logró recabar la atención de un numeroso público que siguió atentamente sus sesiones, concluyendo con el Conversatorio “I.A. y Postpolítica”, a cargo del Dr. Israel Covarrubias, profesor de la facultad de Derecho de UAQ y el Mtro. Jorge Torres, director del portal de noticias “El-post” de México, quienes caracterizaron la forma de hacer política en la era de la I.A. y las neurotecnologías. El evento no solo fomentó el diálogo e intercambio académico, sino que también planteó preguntas cruciales acerca del futuro de la regulación de la IA y las neurotecnologías, logrando demostrar el valor del enfoque colaborativo entre disciplinas para abordar los retos de la tecnología en la sociedad.

Los panelistas y participantes se cuestionaron los límites actuales de las normativas y exploraron la necesidad de desarrollar nuevas propuestas de regulación. La inclusión de enfoques diversos, desde el marco de diferentes perspectivas internacionales, enriqueció los debates que abarcaron tanto aspectos técnicos como cuestiones filosóficas, éticas y legales, subrayando la urgencia de trabajar de conjunto para lograr una regulación global coherente.

El seminario dejó en claro que el futuro de la IA y las neurotecnologías dependerá de la capacidad de las instituciones académicas, jurídicas y políticas para integrar estos avances de manera segura y equitativa, creando garantías para su desarrollo responsable, justo y equitativo, observando el respeto irrestricto a los derechos humanos. Los investigadores y participantes reiteraron el compromiso de seguir explorando estos campos, convencidos de la necesidad de unir esfuerzos para proponer soluciones que sean beneficiosas para toda la humanidad.

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“SEMINARIO INTERNACIONAL DE BIOMEDICINA, ÉTICA Y DERECHOS HUMANOS”: BIOÉTICA, RELIGIÓN Y ESPIRITUALIDAD A DEBATE

José Miguel Hernández Mansilla[1], Gerardo de Vega[2], Benjamín Herreros[3]

Bioética y religión

El “Seminario Internacional de Biomedicina, Ética y Derechos Humanos” celebró su XVII edición los días 7 y 8 de noviembre de 2024, centrado en la relación entre bioética, religión y espiritualidad. Fue inaugurado por Benjamín Herreros, director del Instituto de Ética Clínica Francisco Vallés, entidad organizadora del Seminario, por Fernando Bandrés, impulsor inicial del Seminario, por María Tormo, presidenta de la Fundación ASISA (promotora del Seminario) y por Simone Sato, decana de la Facultad de Medicina de la Universidad Europea de Madrid, donde se celebró este último Seminario.

Dado que su temática era analizar la relación entre bioética, religión y espiritualidad, la conferencia inaugural, sobre ética y religión, corrió a cargo de Manuel Fraijó, filósofo y teólogo español que ha dedicado su vida académica al diálogo entre la fe y la razón, entre la fe y la ciencia. Fraijó inició su discurso con una reflexión sobre la esperanza, una virtud que asocia tanto con la ética como con la religión. Para él, la ética y la religión se entrelazan, complementándose mutuamente para dar sentido a la existencia. En la parte final de su intervención, habló de la relación entre la ética civil y la religiosa: la primera se basa en principios universales y compartidos que garantizan la convivencia en una sociedad pluralista; la segunda, más vinculada a valores trascendentales, ofrece una visión más profunda del sentido de la vida y puede servir como fuente de inspiración para la primera. Ambas no deben enfrentarse, sino complementarse. Fraijó invitó a los oyentes a pensar en la ética y en la religión no como entidades separadas o en conflicto, sino como expresiones complementarias de nuestra humanidad, unidas por un objetivo común: hacer del mundo un lugar más justo, solidario y esperanzador.

Inicio y final de la vida

En las dos primeras mesas redondas se analizó la relación entre bioética, religión y espiritualidad en el inicio y en el final de la vida. La mesa de inicio de la vida contó con expertos de diversas tradiciones religiosas, como el catolicismo, el protestantismo y las religiones orientales desde un enfoque budista. La postura católica expuso una firme defensa de la vida humana desde su concepción, lo cual le sirve de guía para sus posturas bioéticas. El punto de vista del protestantismo ofreció un panorama más diverso, con mayor pluralidad de opiniones dentro de las iglesias protestantes. Si bien muchas comunidades evangélicas coinciden en la defensa de la vida desde la concepción, también existen posiciones que aceptan el aborto en casos específicos. Para el budismo, la vida humana comienza cuando una conciencia entra en un cuerpo material, estableciendo una conexión interdependiente. Este principio otorga al embrión humano estatus moral desde el momento de la concepción, pero también subraya la compasión como eje ético central, por lo cual existen posturas más flexibles que el catolicismo.

La mesa dedicada al final de la vida comenzó con las religiones tradicionales africanas, profundamente ligadas a la naturaleza y los ancestros. Estas ven la muerte no como un fin, sino como un paso hacia una

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dimensión espiritual que conecta a los vivos con los muertos, con rituales en los que los restos humanos, particularmente cráneos, se veneran como una representación tangible de la espiritualidad ancestral. En la perspectiva budista tibetana se narró la práctica del entierro celestial, que ofrece los cuerpos de los fallecidos a los buitres simbolizando un ciclo natural de vida y muerte. Finalmente, se abordó la visión del protestantismo a través de la figura de Albert Schweitzer, teólogo, médico y Premio Nobel de la Paz, cuya ética del "respeto por la vida" marcó una visión profundamente humanista. Para Schweitzer la religión no es una explicación del mundo, sino una construcción ética que da sentido a nuestras acciones. Un elemento transversal en todas las exposiciones fue la exploración del sufrimiento como parte inherente de la experiencia humana. Mientras que las creencias africanas lo integran como una conexión espiritual con los ancestros, el budismo propone transformar el sufrimiento a través de la meditación y la compasión, y el protestantismo lo aborda como un llamado a la responsabilidad y a la solidaridad con el prójimo.

Relación clínica y nuevas tecnologías

El segundo día hubo dos conferencias especiales. La de Pedro Gargantilla, profesor de Historia de la Medicina, fue sobre "Las Religiones en la Historia de la Medicina". Expuso cómo la religión ha estado entrelazada con el desarrollo del conocimiento científico y médico. En muchos momentos, la religión ha proporcionado un marco ético para la práctica médica, mientras que la ciencia ha ido desafiando y redefiniendo las creencias sobre la vida, la enfermedad y la muerte. El diálogo entre lo espiritual y lo científico ha evolucionado, pero sigue siendo un componente esencial en el cuidado de la salud. La otra conferencia, a cargo de Miguel Ángel Sánchez, fue sobre "Bioética y la espiritualidad". Se realizó una distinción entre espiritualidad y religión. La espiritualidad es una dimensión esencial del ser humano, que influye en su desarrollo moral y en su forma de enfrentarse a los problemas éticos. La verdadera espiritualidad no es una serie de dogmas o prácticas religiosas, sino un proceso de transformación interior que permite a las personas ampliar su conciencia y ver más allá de sus propios intereses individuales. Cuando se produce esta transformación, el individuo no necesita códigos morales externos para actuar éticamente, porque la moralidad surge de su propio estado de conciencia.

En la mesa sobre relación clínica se expuso en primer lugar la perspectiva católica, para la cual el profesional de la salud no solo debe tratar, sino también comprender y respetar los valores de sus pacientes. La religión adquiere una importancia fundamental, pues no solo provee marcos éticos, sino también consuelo y significado al sufrimiento. En cuanto al punto de vista judío, existen tres principios fundamentales en la relación clínica: 1) *Pikuaj Nefesh* (Salvar una Vida): preservar la vida está por encima de cualquier otra norma religiosa; 2) *Kavod HaBriyot* (Dignidad Humana): El respeto al paciente es esencial; 3) *Halajá* (Ley Judía): En casos médicos complejos, los pacientes judíos pueden consultar a un rabino. Finalmente, se expuso el islam. Se destacó que muchos médicos desconocen las particularidades de la atención a los pacientes musulmanes, lo que puede generar malentendidos. Algunos puntos clave son la vestimenta y el pudor (prefieren ser atendidos por profesionales de su mismo género y requieren privacidad durante las exploraciones físicas), la dieta Halal y el respeto a la oración y a sus prácticas religiosas.

La última mesa estuvo dedicada a las nuevas tecnologías. Desde el catolicismo se advirtió de los riesgos de poner a la tecnología por delante de todo y de las tesis transhumanistas, una ideología que defiende el uso extremo de la tecnología para superar los límites biológicos de la humanidad. Se alertó de los riesgos de alterar la esencia del ser humano, porque puede erosionar derechos fundamentales y generar nuevas desigualdades. Para la bioética islámica el ser humano es el "califa" o administrador de la creación de Dios, lo cual implica una responsabilidad sobre su propio cuerpo y sobre la naturaleza. La búsqueda de la salud y la longevidad no solo es permitida, sino considerada un deber en la tradición islámica, siempre y cuando no se altere la esencia humana. Por último, se expuso la experiencia espiritual sin religión. Ante la pregunta ¿es posible la espiritualidad sin tecnología? se argumentó que, ya desde la antigüedad, muchas prácticas religiosas y espirituales han sido mediadas por "herramientas tecnológicas", desde los templos a la propia oración, que requiere de una técnica. Sin embargo, la digitalización extrema actual y las nuevas tecnologías plantean nuevos desafíos para la espiritualidad.

Fernando Lolas Stepke: IX Lección Magistral en Bioética James Drane

Fernando Lolas Stepke clausuró el Seminario impartiendo la “Lección Magistral en Bioética James Drane”, acto que ya han realizado destacados bioeticistas, como el propio James Drane, Diego Gracia, Javier Sádaba, Mark Siegler, Mario Bunge, Carlos Viesca o Joseph Fins. Este acto tiene como objetivo repasar la trayectoria de un bioeticista que ha contribuido de forma significativa al desarrollo de la bioética en España y Latinoamérica. En este caso, se debe a la circunstancia añadida de que Fernando Lolas fue amigo y colaborador estrecho durante años de James Drane. La *Laudatio* del orador (publicada a continuación) corrió a cargo de la también psiquiatra María Inés López Ibor, que subrayó la contribución de Fernando Lolas a la estructuración de la bioética desde un enfoque integral, que combina investigación, docencia y práctica clínica.

En la primera parte de la ponencia, Fernando Lolas abordó el desarrollo de la bioética como disciplina y su papel en la regulación de la investigación con sujetos humanos. Resaltó cómo los marcos reguladores han evolucionado para garantizar la dignidad y los derechos de los sujetos de investigación. Habló de su formación intelectual, de su estancia en Heidelberg y de su experiencia en la Organización Panamericana de la Salud, con la creación de un Programa Regional de Bioética para formar a los profesionales sanitarios en los retos morales de la práctica clínica. Aquí apareció la figura de James Drane. Lolas trazó un recorrido por su trayectoria vital e intelectual. Mostró la formación teológica de este pionero de la bioética, su estadía en España para la consecución del doctorado y sus problemas con la iglesia por hacer pública su visión liberal de la contracepción y de la bioética. También señaló cómo Drane promovió la autonomía del paciente en la toma de decisiones sanitarias, creando para ello una escala móvil que evaluaba por primera vez la capacidad de los pacientes para tomar decisiones. Señaló la importancia que tuvo en el ámbito de los cuidados paliativos su obra *Caring to the End*, un trabajo de gran impacto internacional, especialmente en Latinoamérica.

En la parte final de su intervención, Lolas reflexionó sobre los desafíos emergentes en bioética, particularmente en el contexto de la inteligencia artificial y la automatización de la medicina. Subrayó la necesidad de una ética anticipatoria que garantice un equilibrio entre el avance tecnológico y la centralidad del paciente en la práctica médica. La bioética, argumentó, debe mantenerse como un espacio de diálogo y deliberación constante para responder a los problemas que plantea el desarrollo científico. La conferencia finalizó con un reconocimiento al legado de James Drane y una exhortación a continuar promoviendo una bioética crítica y contextualizada.

Conclusión

Bioética, religión y espiritualidad coinciden en buscar lo mejor para el ser humano, en concreto, en lo relacionado con la gestión de la vida y la salud. Ciertamente, las distintas religiones tienen perspectivas diferentes, pero en este Seminario las discusiones han buscado el entendimiento entre los diferentes puntos de vista, en temas tan complejos como la interrupción voluntaria del embarazo o la eutanasia, pudiendo identificarse lugares comunes entre las diferentes tradiciones. A pesar de las diferencias doctrinales, todos los ponentes coincidieron en la necesidad de promover el diálogo interreligioso y una ética que proteja la dignidad de la vida humana. Asimismo, subrayaron la importancia de abordar estas cuestiones con sensibilidad y respeto hacia la diversidad de creencias y perspectivas personales. La integración de las diferentes perspectivas religiosas y éticas ofrece una oportunidad para enriquecer los debates y encontrar soluciones que respeten tanto la dignidad humana como el progreso científico.

Más información en: https://institutoeticaclinica.org/formacion/seminario-de-biomedicina-etica-y-derechos-humanos-xvii/

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LAUDATIO DE FERNANDO LOLAS, CON OCASIÓN DE LA IX LECCIÓN MAGISTRAL EN BIOÉTICA JAMES DRANE, EN EL MARCO DEL "SEMINARIO INTERNACIONAL DE BIOMEDICINA, ÉTICA Y DERECHOS HUMANOS"

María Inés López-Ibor[1]

Ortega, en su ensayo "Temas de Nuestro Tiempo" (1923), introduce el concepto de "razón vital", que sugiere que la vida humana y su cuidado requieren una visión integral que el médico debe tener en cuenta. En esa visión debe incluirse aspectos emocionales, culturales y espirituales de los pacientes, y Marañón nos recordaba que "no hay enfermedades sino enfermos, y que la práctica médica debe adaptarse a la realidad individual de cada paciente". Fernando lolas es reconocido internacionalmente por sus aportaciones en el campo de la bioética, con una visión idéntica, o por lo menos similar, creo yo, que Ortega y Marañón. Sus aportaciones siempre han antepuesto la dignidad del paciente ante cualquier otro interés o avance científico, teniendo en cuenta su singularidad, sin olvidar su propia dimensión espiritual.

Por eso también es un privilegio personal: Fernando conoció y estudió la obra de mi abuelo, Juan José López-Ibor, y participó, desde su posición en la Asociación Mundial de Psiquiatría, en la Declaración de Madrid de 1996, sobre los principios éticos que deben tener los psiquiatras, promovida cuando mi padre era presidente de esa asociación. Recuerdo el cariño y la admiración que mi padre sentía por el profesor Lolas.

La declaración de Madrid ha sido durante 30 años el documento fundamental para establecer los principios éticos en psiquiatría, y solo recientemente ha sido modificada muy parcialmente. En ella se insiste en promover la autonomía del paciente y asegurar que cualquier tratamiento está basado en un consentimiento informado. Enfatiza además en combatir el estigma de la enfermedad mental.

He tenido además la oportunidad de colaborar con él en la Asociación Mundial de Psiquiatría Social, de la que ha sido secretario general hasta hace muy poco.

Para mí sería un trabajo muy grato hacer un recorrido por su extensísimo currículum, que he tenido la oportunidad de leer estos días, pero necesitaría demasiado tiempo. No obstante, quiero destacar algunos puntos.

Nace en Chile en 1948, en momentos en que la medicina chilena experimentaba varios eventos y desarrollos significativos: se debatían propuestas para la "socialización de la medicina", buscando ampliar el rol del Estado en la atención sanitaria. Estos debates sentaron las bases para la creación del Servicio Nacional de Salud, en 1952, inspirado en el National Health Service británico de 1948, y de la carrera de Tecnología Médica, para formar a técnicos de laboratorio clínico, banco de sangre, radiología, física médica y anatomía patológica, con el objetivo de colaborar en la investigación y organización de los hospitales del país.

Estos acontecimientos reflejan un periodo de transformación y modernización en el sistema de salud chileno, con avances en la organización profesional y la formación de nuevos especialistas.

Nace tres años después de que Gabriela Mistral fuese reconocida como Premio Nobel de Literatura, mujer de gran espíritu humanista que revolucionó la educación en su país y que, a través de sus escritos y discursos, abogó por la justicia social, la igualdad de género y la protección de la infancia. Su compromiso con estos valores dejó una huella profunda en el pensamiento social chileno, inspirando a generaciones posteriores a trabajar por una sociedad más justa y equitativa. Supongo que estos aspectos pudieron influir en Fernando Lolas, aunque también su profunda vocación médica.

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Estudió en el Liceo Alemán de Santiago de Chile y, desde joven, comenzó a interesarse por la medicina, cursando sus estudios universitarios en la Universidad de Chile donde también se formó como especialista en psiquiatría para posteriormente trasladarse a Heidelberg y especializarse en medicina psicosomática. Al regresar se interesa por los tres aspectos fundamentales de la medicina: la docencia, la investigación y la clínica, a los que ha dedicado su vida, además de haber ocupado numerosos puestos de gestión muy importantes.

Es profesor de la Universidad de Chile y de la Universidad Central de Chile, director del Centro Interdisciplinario de Estudios en Bioética y del Programa de Ética Global del Instituto de Estudios Internacionales de la Universidad de Chile, y ha sido consultor del comité de ética de la WPA.

Fue vicepresidente de la federación mundial de salud mental, secretario general de la World Association for Social Psychiatry, académico de la Lengua de Chile y correspondiente de la Real Academia Española, académico honorario de la Academia Chilena de Medicina y miembro de honor de la Sociedad Española de Medicina Psicosomática, de la Academia Mexicana de Bioética y de la Sociedad Iberoamericana de Medicina Legal. Es *doctor honoris causa* de las universidades San Marcos y Ricardo Palma, de Lima, de las universidades de Córdoba y de Cuyo, en Argentina, y de Jequitinoha e Mucurí, en Brasil. Es profesor honorario de numerosas universidades de Europa, EE. UU. y Latinoamérica.

Durante cuatro años fue miembro del *International Bioethics Committee* de Unesco, abocado principalmente a la revisión y comentario de la declaración sobre bioética y derechos humanos de 2005. El mismo destaca que “como funcionario de OPS, entre 1998 y 2010, trabajé dirigiendo la unidad de bioética y formando profesionales en toda Iberoamérica con ‘*Grants*’ de NIH, gracias al apoyo que entonces nos prestó Diego Gracia y otros expertos de la Universidad Complutense de Madrid”.

Su obra escrita es extensísima, habiendo publicado más de 500 artículos originales en revistas nacionales e internacionales, y más de 60 libros. Es miembro del comité editorial de numerosas revistas, siendo sus aportaciones un referente en aspectos relacionados con la ciencia y humanismo, entre los que me atrevería a destacar dos muy recientes: “La salud mental como dimensión moral: desafíos para la psiquiatría y las ciencias del comportamiento” en *Mente y Cultura*, publicado hace cuatro años. En él considera a la psiquiatría como profesión camaleónica y dice: “quisiéramos miradas integradoras, holísticas que, así como velan por la salud, satisfagan deseos de dignidad, justicia y equidad. Desearíamos que la bioquímica cerebral se armonizara con especulaciones sobre espíritu y alma”.

En “A propósito de metáforas: ‘inteligencia artificial’ y necesidad de una ética anticipatoria”, de este mismo año, señala: “las expresiones metafóricas sugieren que tratamos con seres pensantes. ‘Regular’ la inteligencia artificial es como regular cerebros. Tener neuroleyes y neuroderechos se confunde con tener regulaciones de ‘inteligencias’ naturales y artificiales. Hay entusiasmo y temor. Como señalaba José Ortega y Gasset hace más de 70 años, uno de los temas que en los próximos años se va a debatir con más brío es el sentido, ventajas, daños y los límites de la técnica, y deberemos estar atentos”.

No quisiera terminar sin mencionar sus aportaciones en temas tan importantes como la salud mental en situaciones de desastres y catástrofes, ahora y en los próximos meses tan necesarias en Valencia. Destaca la necesidad de una perspectiva interdisciplinaria que integre aspectos éticos, sociales y culturales en la atención de la salud mental durante y después de desastres. Subraya la importancia de fortalecer la resiliencia comunitaria y de implementar intervenciones psicosociales que promuevan el bienestar y la cohesión social en contextos de crisis, algo tan necesario en estos momentos.

Querido Fernando, estamos muy agradecidos por tu trabajo a lo largo de los años y estoy segura de que, en tiempos tan complejos como los que estamos viviendo, tu legado será fundamental para las nuevas generaciones.

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CENTRO INVESTIGACIÓN EN ESTUDIOS SOCIO JURÍDICOS, CRIMINOLÓGICOS Y ÉTICOS
VICERRECTORÍA INVESTIGACIÓN Y POSGRADO
UNIVERSIDAD CENTRAL DE CHILE

Carolina Valdebenito Herrera[1]

En el proceso de resolución y establecimiento del Centro de Investigación en Estudios Socio jurídicos, Criminológicos y Éticos (CIESCE), Facultad de Derecho y Dirección de Investigación y Doctorados pertenecientes a la Vicerrectoría de Investigación y Posgrado, y fundamentada en la resolución 7.345 del 14 de noviembre de 2024, que aprueba la creación del Centro, tuvo lugar una Reunión Académica Ejecutiva en el Campus Vicente Kovacevic VKII de Universidad Central de Chile, entre académico/as de universidades chilenas y extranjeras.

Se contó con la participación del Dr. Jesús Armando Martínez, Universidad Autónoma de Querétaro; Dr. Benjamín Herreros, Universidad Complutense de Madrid: Dr. Juan Alberto Lecaros, director del Observatorio de Bioética Universidad del Desarrollo: Dra. Ángela Arenas, Universidad Finis Terrae, directora del Laboratorio Avanzado de Investigación en Ciencia de Datos para el Derecho (LIACDD); Dra. Natalia Herrera, Universidad de Tarapacá de Chile: Dr. Fernando Lolas, director del Centro Interdisciplinario Estudios en Bioética, Universidad de Chile, y de la revista *Acta Bioethica*, Profesor Titular Universidad de Chile y Universidad Central de Chile, entre otros, además de la participación del director del Centro, Dr. Profesor Edison Calahorrano, su coordinadora Dra. Profesora Carolina Valdebenito Herrera, Dra. Profesora Sara Moreno, Dra. Profesora Isabel González, Dra. Profesora Lorayne Finol y Dr. Profesor Sergio Fuenzalida.

A este grupo se unirán el Dr. Francisco León Correa, presidente del Comité de Ética de la Universidad Central, socio fundador y Profesor Titular de la Universidad Central, así como el Dr. Carlos Viesca, médico y Profesor Titular en la Universidad Nacional Autónoma de México.

El propósito de esta concertación de destacados profesores e investigadores fue conocer lo que se hace en distintos centros de investigación relacionados con áreas similares a las del Centro de Investigación en Universidad Central en temas relacionados al Derecho, Ética y Bioética.

En la discusión se observó que existen temas nuevos, contingentes y clásicos desde las áreas del Derecho, la salud y la ética, siendo importante la manera en que ellos se comunican e interrelacionan en un contexto sociocultural altamente digitalizado.

En la convergencia de espacios comunes desde la ética y la bioética aparece el concepto de educación en reiteradas ocasiones, como una necesidad para afrontar nuevas demandas éticas en los nuevos espacios de la salud, del Derecho y de los fundamentos filosóficos bioéticos.

Tras esta reunión se espera generar un plan estratégico de trabajo interuniversitario para evaluar posibilidades concretas de postulación a fondos concursables, nacionales e internacionales, así como la publicación de material científico a corto, mediano y largo plazo.

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LOLAS STEPKE, FERNANDO Y RODRÍGUEZ YUNTA, EDUARDO
Perspectivas en bioética
Editorial Universitaria, Santiago de Chile, 2024. 276 págs.
ISBN: 978-956-11-3071-5

Pablo Ruiz-Tagle Vial[1]

Hay quienes sostienen que la bioética es un campo multidisciplinario, que se ocupa de los problemas éticos relacionados con la vida en términos generales. Este libro aborda ese sentido amplio y también uno más específico, centrado en cuestiones relacionadas con la vida humana en el contexto de la medicina. Se plantea no tanto determinar qué deben hacer exactamente los médicos en situaciones concretas, sino comprender qué tipos de conceptos o principios sirven para pensar y enfrentar una amplia gama de dilemas.

Si tuviera que mencionar las competencias de los autores para abordar estos asuntos me tomaría todo el tiempo de la presentación. Eduardo Rodríguez es doctor en Genética, bioeticista y teólogo moral. Ha trabajado en instituciones internacionales y nacionales, y, como sacerdote, ha trabajado con poblaciones vulnerables. Se ha desempeñado en centros de la Universidad de Chile y ha escrito numerosos artículos y capítulos de libros. Fernando Lolas, por su parte, es médico psiquiatra, especialista en Medicina Psicosomática, con estudios de posgrado en Alemania y Estados Unidos, doctor "Honoris Causa" por distintas universidades y profesor en la Universidad de Chile, Miembro de Número de la Academia Chilena de la Lengua y Correspondiente de la real Academia Española, miembro de comités internacionales de bioética. Es autor de diversas publicaciones sobre bioética, psiquiatría y medicina antropológica.

Ambos autores habían publicado antes en conjunto el libro *Bioética y humanidades médicas* (2020) que, en sus distintos capítulos, aborda temas como el inicio de la vida y el estatuto del embrión, el envejecimiento o la eutanasia. Ya en esa publicación dan cuenta de esa visión humanista de la medicina que distingue a los mejores sanadores. Su esfuerzo se entronca con el punto de vista que representa el doctor Augusto Orrego Luco, el doctor Armando Roa y el doctor Alejandro Goic, entre otras personalidades que se destacan por esta notable impronta.

En este nuevo libro se tratan desde los orígenes de la bioética hasta la ética médica y la toma de decisiones, precisando que hay ciertos principios que la guían. Las decisiones muchas veces deben enfrentar una serie de dilemas bioéticos contemporáneos, como aquellos vinculados con los límites de la aplicación de la tecnología, la preservación del medio ambiente y temas de salud pública o global.

En uno de los capítulos se analiza la distinción entre ética y moral, considerando la segunda como un conjunto de prácticas sociales que rigen la conducta de personas o grupos. La ética, en cambio, sería una forma de reflexión sobre el comportamiento humano que busca formular, fundamentar y aplicar principios que favorezcan la convivencia. La bioética, por último, sería una forma de articular principios de comportamiento y reflexión distinta de la ética tradicional, en dos aspectos: la deliberación basada en el diálogo y una visión integradora e interdisciplinaria, por ejemplo, al hacerse cargo de los avances técnicos y científicos. Un "consecuencialismo dialógico" sería para los autores la mejor forma de caracterizarla, centrada más en los procedimientos que en las convicciones, a efectos de la legitimidad de la decisión moral. En otro lugar del libro la definen como un "metadiscurso moral", cuya principal función es lograr pluralismo teórico o diálogo en un área que suele ser capturada por el monólogo.

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En cuanto a los principios, señalan que los tradicionales o clásicos de la bioética —que en algún momento llaman "el mantra de Georgetown"— son: autonomía, beneficencia, no maleficencia y justicia. Pero, según argumentan, las circunstancias y su aplicación han generado nuevos principios, como los de solidaridad, precaución, responsabilidad, sostenibilidad o protección de las personas vulnerables, algunos de los cuales son analizados en detalle en este libro, como el de no maleficencia o el de solidaridad, específicamente en relación con el envejecimiento de las personas hasta edades avanzadas, lo que es ya una realidad demográfica mundial.

También destacan que la expansión de los principios a la práctica clínica ha llevado al método deliberativo en comités como algo característico de la práctica bioética: su carácter dialógico, la deliberación en grupos para buscar soluciones, es decir, la institución del comité como una instancia procedimental para articular e integrar las discrepancias.

Así, en un capítulo del libro se plantea la ética en cuanto diálogo y la "imaginación moral" como ponerse en el lugar de otros cuando no es posible ese diálogo. Esto permite una ética dialógica, basada en procedimientos. Señalan los autores:

Para las profesiones —la medicina y el Derecho, que tratan directamente con personas— esto implica la virtud de la prudencia. No todo lo que es posible debe hacerse ni todo lo que podría decirse debe decirse. El tiempo, el lugar, la circunstancia, determinan cuándo y cómo el diálogo, fuente y fundamento de la moral, será puesto eficazmente a resolver dilemas.

Efectivamente el Derecho y la medicina deberían basarse, aunque tal vez no siempre lo hagan, en la prudencia.

Pero hay otros puntos en los que en esta obra el Derecho y la bioética se tocan. Por ejemplo, en el ámbito de los derechos humanos, porque tal discurso tiene la peculiaridad de basar su juicio estimativo en el diálogo:

> En materias aún no fijadas en textos canónicos, la práctica jurisprudencial, todos los involucrados o afectados (*stakeholders*) deberían participar en la toma de decisiones.

Esto, según los autores, se parece al concepto de "democracia participativa", por oposición a la representativa, pues el poder no radicaría en representantes.

Y en otro capítulo se señala que es importante, tanto para el derecho como para la ética, el "equilibrio reflexivo", lo que por cierto nos recuerda a John Rawls, que en 1970 publicó su famosa obra *Una Teoría de la Justicia*. Dice el texto comentado:

> El equilibrio reflexivo se alcanza cuando después de un proceso de deliberación se logra ajustar las creencias e intuiciones morales propias de cada psicología, de forma que se logre un todo coherente en que cada creencia sirve de apoyo para las demás.

No puedo detenerme en estas ideas de democracia representativa o equilibro reflexivo, pero quiero destacar la capacidad del libro para generar puntos de vista distintos y diálogos, o incluso debates posibles. Se perciben como de gran utilidad para iluminar y resolver cuestiones concretas de la práctica médica

Quisiera detenerme en uno de ellos. En el capítulo "Consideraciones sobre la narrativa del morir 'correcto'", los autores se dedican al análisis del morir como proceso humano antes de la muerte, proponiendo el concepto de "ortotanasia" para superar el de "eutanasia", que se estima como reductor, ya que considera solo a quien va a morir y a los agentes médicos. Y el de "tanatoiatría", como una especialidad médica dedicada de manera "holística" a conceptualizar y abordar este proceso en sus aspectos personales y sociales, cuyo ejercicio requiere un talante dialógico que se identifica con la bioética. Sus consideraciones son muy amplias, desde la literatura clásica hasta la sociología, la historia o la novela del siglo XX.

En su libro anterior, *Bioética y humanidades médicas*, los autores, en el capítulo "Eutanasia y cuidados paliativos", abordaban de manera detallada el debate sobre la eticidad de permitir la eutanasia voluntaria y el suicidio asistido para enfermos terminales, presentando los argumentos y contrargumentos al respecto, así como la dificultad de la concepción de "cuidados paliativos".

Enfrentado a decisiones de este tipo, el Derecho tiene algo que decir. Si hay, por ejemplo, desde el punto de vista del Derecho, diferencias entre los casos en los que los médicos matan a los pacientes o los ayudan a suicidarse, y aquellos en que dejan morir a los pacientes al aceptar no administrarles tratamientos que prolongan la vida. Algunas de estas diferencias pueden ser importantes: puede ser que la eutanasia activa tenga más probabilidades de ser objeto de abuso, lo que da lugar a un asesinato no consentido, o que la eutanasia activa, más que la eutanasia pasiva, socave normas culturales importantes en torno a la vida y nuestra autoridad sobre ella. Sin embargo, otras diferencias pueden modular la importancia de la distinción, y resulta una gran paradoja afirmar que la eutanasia activa es perjudicial para el paciente, en circunstancias que los pacientes que la solicitan piensan que la continuación de la vida en su condición es un daño y el fin de la misma un beneficio.

En Chile no hay autorización legal para la eutanasia y el proyecto al respecto ha estado dormido por seis años. Otra situación distinta es la que existe respecto de la eutanasia en el Derecho estadounidense. El libro de los profesores Lolas y Rodríguez dialoga con algunos de los casos resueltas en EE.UU. sobre la eutanasia y el derecho a morir, no por estar de acuerdo con esas soluciones, sino para preparar el debate que es posible anticipar en estas cuestiones en Chile.

Sobre el caso norteamericano, en su libro *El Derecho de las libertades* (1996) el jurista y filósofo Ronald Dworkin presentaba el caso de Nancy Cruzan, quien, en 1983, a los 24 años, quedó en un estado vegetativo permanente producto de un accidente automovilístico. Los padres solicitaron desconectarla para que muriera en paz. Pero el hospital rehusó hacerlo sin una orden judicial, por lo que presentaron un recurso. El tribunal concedió la orden, pero ésta fue apelada y el tribunal superior la revocó porque los tutores legales carecían de pruebas de que la paciente misma hubiera deseado ser desconectada en tales circunstancias, a pesar de que un testigo afirmaba que así lo había dicho. La familia de la paciente apeló a la Corte Suprema de los Estados Unidos que, en voto dividido (cinco contra cuatro), en 1990, mantuvo a decisión de negar la desconexión. Los votos redactados tanto por jueces de la mayoría como por los disidentes son muy interesantes: plantean si las personas tienen derecho constitucional a rechazar un tratamiento de soporte vital si están en un estado vegetativo y quiénes podrían ejercerlo si ellas no han señalado nada antes, o bien si los Estados tienen un derecho a mantener con vida a sus habitantes. En agosto de 1990 los padres acudieron nuevamente al tribunal inferior con nueva evidencia (más testigos que señalaban la voluntad de la paciente de no vivir en esas circunstancias), pero esta vez la fiscalía no se opuso a la petición de los padres y el tribunal accedió a ella. Se detuvo la alimentación e hidratación y la paciente murió.

Agrega Dworkin otro caso, como adenda de su libro recién citado, uno de 1994 y que según él podría transformarse en el *Roe vs. Wade* (que en 1973 permitió el aborto por un plazo limitado en Estados Unidos y que hoy ha sido revertido por la Corte Suprema de EE.UU.) respeto de la eutanasia. En *Washington vs. Glucksberg*, una jueza del Tribunal del Distrito Federal echó abajo la ley en contra de la asistencia al suicidio del Estado de Washington, de 140 años de edad, y declaró que los pacientes terminales competentes tienen un derecho constitucional a recibir asistencia para morir por parte de un profesional de la salud que lo consienta.

Cuando Dworkin agregó esa adenda a su libro en 1994, la Corte Suprema aún no se había pronunciado sobre el caso. Tampoco lo había hecho cuando, en 1996, Dworkin comentó en la *New York Review of Books* ese caso, en el momento en que el tribunal superior revocó la decisión de la jueza. Entonces agrega un caso más: *Quill vs. Vacco*, en que tres médicos desafiaron la decisión del Estado de Nueva York respecto de pacientes moribundos de cáncer y sida que sufrían un gran dolor, que ya no podía aliviarse con tratamientos y querían contar con medicamentos con el fin de, en palabras de uno de ellos, "acelerar la muerte de manera humana y segura". El juez de primera instancia lo desestimó, pero los médicos apelaron. El tribunal superior estuvo de acuerdo en que no había una tradición, ni precedentes en EE.UU. acerca de un derecho a la eutanasia, pero encontró una manera de declarar inconstitucionales las leyes de Nueva York. Sostuvo que, dado que Nueva York permitía a los pacientes ordenar que se les quitaran los sistemas de soporte vital (como decía la decisión Cruzan), se negaba la igualdad de protección de las leyes cuando no se permitía a los pacientes que no estaban en soporte vital la ayuda de los médicos para terminar con sus vidas. Se vulneraría la cláusula constitucional de igualdad de protección.

Estos casos se decidieron por la Corte Suprema al año siguiente, en 1997. En *Washington vs. Glucksberg* la Corte sostuvo por unanimidad que el derecho al suicidio asistido en los Estados Unidos no estaba protegido por la cláusula del debido proceso. Y en el caso *Vacco vs. Quill*, también por unanimidad, que la prohibición de Nueva York del suicidio asistido por médicos era constitucional y que impedir que los médicos ayudaran a sus pacientes, incluso a aquellos con enfermedades terminales o con mucho dolor, era un interés estatal legítimo. Es decir, que no existía una garantía constitucional de un "derecho a morir".

Cabe señalar que, en un libro previo, *El dominio de la vida* (1993), Dworkin defiende la permisibilidad moral y legal de la eutanasia. Para fundar esta posición Dworkin se apoya en la distinción entre intereses experienciales y críticos. Los intereses experienciales son aquellos que no se deben negar, a través de la muerte o de otras maneras, como las experiencias placenteras; los intereses críticos se basan en los juicios de las personas sobre lo que hace que su vida sea buena o que valga la pena vivirla. La opinión sobre el tipo de muerte que es apropiada para cada uno se basa en su juicio personal sobre la forma de su vida y puede considerar que ciertas formas de morir son indignas y ciertos tipos de existencia que terminan en la muerte, como el coma prolongado, son maneras inadecuadas de terminar la vida que uno ha elegido. Algunas terminaciones de la vida, incluso si no son dolorosas ni malas experiencialmente para una persona, pueden considerarse según Dworkin no ajustadas a sus intereses críticos.

En fin, presento estos argumentos porque, como los mismos autores señalan en su artículo sobre la eutanasia:

Tal vez el papel de la reflexión bioética sea invitar e incitar al diálogo entre personas que honestamente difieren sobre cómo habría que encarar el vivir y el morir dignamente.

Comparto el punto de vista más tradicional de los autores para enfrentar estos dilemas tan relevantes. Sin embargo, agradezco el que nos den noticia sobre las decisiones extranjeras que pueden imponer una forma de resolver estos asuntos en Chile. Porque, al igual que en el efecto mariposa, un leve movimiento de las alas de una mariposa en Japón puede derivar en un maremoto en Chile. Una decisión de la Corte Suprema norteamericana puede ser objeto de trasplante y adopción irreflexiva en Chile, como "*lege ferenda*" o como norma válida y vigente. Ese es otro de los méritos de este libro: presentarnos, como una especie de serendipia, argumentos extranjeros que podemos o no usar en nuestro país para resolver estos conflictos.

En fin, es, como digo, un aporte al diálogo que este libro excelente, despierta.

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LAHERA, GUILLERMO.
Las palabras de la bestia hermosa. Breve Manual de Psiquiatría con alma. Debate, Penguin Random House, Barcelona, 2024. 247 págs. (ISBN 978-84-19951-00-7)

Fernando Lolas Stepke[1]

Libros como éste son difíciles de clasificar y difíciles de escribir. Los expertos (o sedicentes expertos) pueden pensar que se omite información relevante, los profanos y la gente común que faltan mayores aclaraciones. Quienes los escriben suelen tener en mente una audiencia específica o dirigirse al público en general.

Estas dificultades quedan sorteadas en este libro de Guillermo Lahera mediante un entramado de reflexiones autobiográficas surgidas en la profesión de médico psiquiatra, informaciones adecuadas sobre etiología y patogenia de los trastornos de la ideación y el comportamiento, y un estilo llano, sugerente y atractivo.

Intrigante el título, permite recordar las palabras de un psicoanalista que solía decirme que la fábula de la Bella y la Bestia era muy apropiada para su oficio. Quienes reciben el rótulo de “pacientes” pueden sentirse Bestias pero desean reconocimiento por la belleza que toda imperfección esconde. Sin negar el sufrimiento y sin desconocer aquello de la “conciencia de enfermedad” —que tanto abruma a los principiantes—, quienes piden ayuda por el menoscabo, la discapacidad o la minusvalía lo hacen sabiendo que el estado perfecto es tanto una aspiración como un logro. Convencerles de que no basta a veces la voluntad o el deseo para sentirse bien, y que la salud plena es en el fondo esperanza (u “horizonte de esperanza”), conseguida con ayuda de una persona extraña que se supone “sabe”, es la primera tarea de la relación terapéutica.

Las “profesiones éticas” son aquellas que tratan con personas y responden a sus necesidades o deseos con empatía, comprensión y conocimiento. Pero también, como decía el gran clínico William Osler, con “ecuanimidad”. Una cierta distancia que no obnubile el juicio sin perder calidez o comunicación interpersonal. Que esto es difícil bien lo saben quienes se inician en el oficio, y sin duda habrán escuchado muchas veces aquello de fusionar “ciencia” y “arte”, sin que se aclare dónde termina una y empieza lo otro. La *praxis comunicativa* que se expresa en el diálogo terapéutico tiene múltiples intereses (*Inter-Esse*, lo que está “entre” los seres) y el “contrato” implícito entre solicitantes y dadores de ayuda no asegura “resultados” sino “buenas intenciones”. Las “*praxiologías*” o “ciencias de acciones” (como la medicina) no “producen” objetos (la salud, por lo menos, no es tal) sino se basan en buenas prácticas y deseables intenciones. La ética aquí, en su más prístino sentido, consiste en recordar que no puede haber médico bueno (en el sentido de buena o virtuosa persona) si antes no es buen médico (aquel que domina el arte), base de la tradición hipocrática. El imperativo técnico es el imperativo primero.

La lectura de este libro mezcla “viñetas” ágiles, breves, sustantivas, con reflexiones personales e infor-

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mación fáctica. También con alusiones a la biografía del autor, lo que de inmediato forja una complicidad con quienes leen. Quizá alguien encuentre las explicaciones técnicas algo simples, pero ello no es óbice para valorarlas como estímulos para aprender más. Sorprenden las numerosas referencias cinéfilas y literarias, que son como los refranes del Quijote, sal y pimienta de la narración y estímulo para indagar más.

Dar noticia de esta publicación en *Acta Bioethica* indica que interpela no solamente a psiquiatras, psicólogos y profesionales en general, sino también a personas de muy variada condición que deseen reflexiones, sugerencias y amena lectura.

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BURROW, JOHN.
A History of Histories. Epics, Chronicles, Romances and Enquiries from Herodotus and Thucydices to the Twentieth Century.
Allen Lane, Penguin Books, London, 2007 (553 págs.)
ISBN 978-0-713-99337-0

Fernando Lolas Stepke[1]

Justifica llamar la atención sobre un libro de historia en relación con la ética o la filosofía práctica por muchos motivos.

La dimensión histórica del pensamiento sobre moral y costumbres, especialmente cuando se codifica lingüísticamente en normas éticas, es insoslayable. No se trata de ignorar que pueden existir normas universales para el comportamiento humano. Sin embargo, se comprueba diversidad en el registro histórico. Cabe preguntarse si cuando se habla de derechos humanos o prohibiciones sociales en el presente se hace justicia a lo que generaciones humanas anteriores entendieron como normas de convivencia humana.

Por otra parte, la historia no siempre es lo “que en realidad ocurrió” (como decía Leopold von Ranke, “*was in der Tat geschehen ist*”). Quienes escriben lo que llamamos historia son personas que valoran, juzgan, aprueban o condenan. El mismo desarrollo de la capacidad de interrogar el pasado provoca reevaluaciones, formas distintas de juzgar hechos y épocas, denominaciones que parecen capturar lo esencial de un período o, incluso, el descubrimiento de testigos o personas que en el pasado hablaron o escribieron sobre su contemporaneidad. La historia es memoria modificada por el presente desde el cual se escribe. Como toda memoria, es invención del pasado.

También debe considerarse la finalidad. Es distinto listar acontecimientos en anales o recopilaciones de sucesos, crónicas que exaltan hechos o personas, biografías que escudriñan personalidades merecedoras de atención, tratados que proponen sacar lecciones del pasado para afrontar el futuro o documentos que analizan o sintetizan situaciones y circunstancias.

De estas múltiples finalidades del trabajo histórico da cuenta el libro de John Burrow. Es valiosa fuente para estudiar escritos relevantes. Su énfasis no está en los hechos o las personas objeto de historia sino en los historiadores o narradores. Esto lo hace particularmente valioso para estudiar el trabajo histórico y sus diferentes finalidades. Una lectura atenta a sus resonancias y connotaciones puede enseñar sobre la ética implícita no solo en la selección de los temas que privilegiaron distintos autores sino también en la forma de narrar.

Las presentaciones de obras clásicas son un comentario razonado de cada una, con apreciaciones personales y ocasionales referencias al contexto en el cual fueron escritas. De allí puede inferirse, no siempre de modo explícito, cuáles fueron los contextos y la vida común tras la preparación de las obras e, indirectamente, lo que en el relato se consideró digno de atención. Tal selección temática indica qué se

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valoró como hecho histórico o período relevante, lo cual ya implica una valoración. Y toda valoración es juicio moral.

Por ejemplo, Salustio, en sus estudios sobre la conjuración de Catilina y la guerra de Jugurta, aparte de narrar hechos se aplica a describir los signos de corrupción perceptibles en la sociedad romana. Tácito, hablando sobre Germania, sirvió de ejemplo sobre lo que era un pueblo bárbaro con virtudes apreciables. Geoffrey de Monmouth, al incluir referencias a personajes casi mitológicos, como el Rey Arturo, mezcla elementos fantasiosos con revelación de hechos en la tradición de Heródoto. Éste puede considerarse un etnógrafo que, a través de informantes (en los que no siempre cree), habla de Egipto y Babilonia. La preservación de lo digno de memoria, su objetivo declarado, le permite indagar por costumbres y prácticas comunicadas por personas y no basadas en información documental. La Revolución Inglesa de 1649 es objeto de obras que toman partido por el Rey o el Parlamento, y revelan juicios morales que luego serán revisados por otros historiadores a tenor de distintas circunstancias.

La principal función de esta historia de las historiografías no es tanto revisar los hechos o las épocas sino indagar por qué fueron objeto de narrativas. La ética no es tarea manifiesta pero está infusa en el trabajo. Es tarea de quienes estudian reconstruirlas a través de una empatía lectoral que, inevitablemente, se confundirá con las propias convicciones. Los textos viven en sus lectores. Son siempre ambiguos y admiten interpretaciones.

Independientemente de que se escriban “historias sociales” o los hechos y las circunstancias de “personajes importantes”, la narrativa histórica es venero de intuiciones y sugerencias para reconstruir el clima moral. No solo de lo que es objeto de las historias sino de quienes las escriben. Se trata de un proyecto de investigación que, bien realizado, podría contribuir a superar la simplicidad de quienes pontifican sobre ética y bioética sin considerar el “cuándo” y el “cómo” de prácticas sociales que demuestran los cambios sociales. Y tales cambios sociales, objeto de la historia, son esenciales para juzgar lo que ocurre en el presente. Lo que se llama “*Wirkungsgeschichte*” o historia de los efectos y consecuencias de un hecho o su recepción en la posteridad debe ser parte de la apreciación.

La tentación inherente a muchas “filosofías de la historia” es proponer finalidades .“La historia como hazaña de la libertad”, para parafrasear a Benedetto Croce, “la consumación de los tiempos y la venida del Mesías”, en la escatología judeocristiana, el “mito del progreso”, “el eterno retorno”, “el fin de la historia”, la “conquista de los derechos”, entre otras, son finalidades subyacentes a muchos textos. Es un trabajo de meta-ética. A menudo los contemporáneos no son buenos jueces de los acontecimientos y la tentación de descubrir precursores, o inventarlos, sirve tanto para fundamentar acciones como para justificarlas.

En resumen, la historia es fundamental en toda meta-ética. Sin considerarla se corre el riesgo, que ya es hábito, de pensar que lo que hoy nos ocupa es lo más importante o, lo que es peor, buscar justificaciones en el pasado para acciones del presente.

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CÁRDENAS KRENZ, RONALD

¿Libertad individual vs. bien común? Lecciones de la pandemia y nudges *como estrategia de vacunación*

Colex, A Coruña (España), 2024, 200 págs. ISBN 978-84-1194-711-4

Esther Torrelles Torrea[1]

Fue un honor para mí participar en la presentación del libro del Dr. Ronald Cárdenas Krenz titulado *¿Libertad individual vs. bien común? Lecciones de la pandemia y* nudges *como estrategia de vacunación*, en un espacio tan especial como es el Colegio de Abogados de Lima, una institución con una reputada tradición y reconocimiento presidida por el ilustre Sr. Raúl Canelo.

Al Dr. Cárdenas Krenz lo conocí a través de las pantallas. Iniciábamos el curso de especialización en Derecho privado, en marzo de 2021. Me llamó la atención los saludos afectuosos de sus compañeros a medida que se iban incorporando a la red. Intuí que ahí había una persona con carisma.

Su trayectoria profesional da fe de ello: abogado, magíster en Derecho Civil; magíster en Bioética y Biojurídica; doctor en Derecho por la Universidad Pública de Navarra y la Universidad de Salamanca. profesor y decano de la Facultad de Derecho de la Universidad de Lima, UNIFE y ESAN; miembro de la Academia Nacional de Derecho y Ciencias Sociales de Córdoba; miembro de la Pontificia Academia para la Vida; superintendente de los Registros Públicos, presidente del Consejo del Notariado e investigador del diario *El Comercio*, en el Perú; miembro del Equipo Regional de Moderadores de la fundación Friedrich Naumann; corresponsal de la revista *Perfiles Liberales*, y un largo etcétera.

Los orígenes del libro se remontan en la confianza que depositó la Universidad de Lima en la Universidad de Salamanca para la creación de unos cursos de formación. A raíz de ello y tras finalizar el curso, mucho de los participantes en el mismo, profesores de alto nivel de la Universidad de Lima, se matricularon en el programa de doctorado en Derecho privado, interuniversitario entre el Universidad de Salamanca (USAL) y la Universidad Pública de Navarra (UPNa).

La primera tesis defendida de ese ilustre grupo de profesores que conformaron la primera edición del curso de especialización en derecho privado ha sido la del Dr. Cárdenas, bajo la dirección de la profesora María Jorqui Azofra, en la UPNa, cuya directora del programa en dicha Universidad es la profesora Mª Ángeles Egusquiza Balmaseda.

El objetivo del libro es analizar la libertad individual y los límites de la intervención del Estado en nuestras vidas en el ámbito de la salud, analizados a partir de la experiencia de la pandemia y las vacunas para hacer frente a la enfermedad. Como bien nos enseña el Dr. Cárdenas Krenz, la libertad implica la capacidad de decidir, pero muchas veces actuamos afectados por sesgos, prejuicios y ruidos, además de factores emocionales, o razones de comodidad e inmediatez. Los gobiernos se encontraron con amplios sectores de la población reacios a vacunarse, invocando diversas razones, planteándose así

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la discusión acerca de los límites de la autonomía personal ante la búsqueda del bien común. En esta circunstancia, los Estados debieron adoptar diversas medidas, más o menos impositivas, surgiendo entre otras alternativas la aplicación de *nudges*, como pequeños empujones para estimular a las personas a vacunarse. La obra que se presenta profundiza, precisamente, en la relación entre la libertad individual y el bien común, buscando extraer algunas lecciones a partir de la experiencia de la pandemia, evaluando la posibilidad de recurrir a *nudges* en situaciones que interesan a la salud pública, sin vulnerar derechos fundamentales.

Es un libro multidisciplinar entre el Derecho y la bioética, y por ello da respuestas a interrogantes éticos, tarea nada sencilla, pues hay que interpretar los principios y pueden colisionar los unos con los otros, en especial, la autonomía del individuo y la voluntad de beneficiarlo. Y eso precisamente se consigue en este libro, una buena interpretación de principios fundamentales y capacidad para extraer el ángulo singular de las cosas.

Es un libro que tiene sintaxis: empieza con una frase interrogativa, el tema que va que desarrollar, y se va llenando de subordinadas (cuatro capítulos), acabando con doce conclusiones claras y concisas. El libro construye una oración compleja, sin tropiezos semánticos y bien trabajado.

La obra desbrava, doma, pues propone reflexiones muy pertinentes en materias que son el núcleo del nuevo Derecho privado. Es capaz de atrapar al lector desde el primer momento a través de una redacción fresca, cuidada y muy personal. Por ello, en nombre de los estudiosos del Derecho, agradezco al autor haber plasmado su investigación y estudio de varios años en esta obra.

Algunos libros son inversiones, otros son facturas, este es una inversión.

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