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RESEARCH

Bioethical conflicts in end of life care

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Abstract

This integrative review of the literature aims to identify the main conflicts between patients in palliative care, family and healthcare team from the point of view of the principlist ethics. A search was performed on databases, generating a final sample of 12 publications that, after being evaluated by the content analysis technique, enabled the emergence of three thematic categories: professional conduct – respect for the patient's autonomy and the principle of beneficence; bioethical principles in the context of end of life care; and bioethical dilemmas in this context. We concluded that autonomy and beneficence stand out in the palliative care, ratifying the idea that the patient is the main actor and needs a humanized and comprehensive health care. In addition, we found some weaknesses in the process of education and communication in the healthcare team, patient and family relationship.

Keyword: Ethics. Patient care team. Professional-family relations. Patient participation. Hospice Care.

Resumo

Conflitos bioéticos nos cuidados de fim de vida

Esta revisão integrativa da literatura tem por objetivo identificar os principais conflitos entre paciente em cuidados de fim de vida, familiares e equipe de saúde sob a ótica da ética principlista. A partir de pesquisa em bases de dados, chegou-se à amostra final de 12 publicações que, após avaliada pela técnica de análise de conteúdo, revelou três categorias temáticas: condutas profissionais – respeito à autonomia do paciente e ao princípio da beneficência; princípios bioéticos no contexto dos cuidados de fim de vida; e dilemas bioéticos nesse mesmo cenário. Autonomia e beneficência são fatores preponderantes nos cuidados de fim de vida, ratificando a ideia de que o paciente é o ator principal e necessita de assistência humanizada e digna. Além disso, constataram-se fragilidades no processo de educação e comunicação, e na relação entre equipe, enfermo e familiares.

Palavras-chave: Ética. Equipe de assistência ao paciente. Relações profissional-família. Participação do paciente. Cuidados paliativos na terminalidade da vida.

Resumen

Conflictos bioéticos en los cuidados al final de la vida

Esta revisión integrativa de la literatura tiene como objetivo identificar los principales conflictos entre el paciente con cuidados al final de la vida, los familiares y el equipo de salud, bajo la óptica de la ética principlista. A partir de una investigación en bases de datos, se llegó a una presentación final de 12 publicaciones, que después de ser avaliada por la Técnica de Análisis de Contenido, permitió emerger tres categorías temáticas: respeto a la autonomía del paciente y el principio de la beneficencia; principios bioéticos en el contexto de los cuidados al final de la vida; dilemas bioéticos en el mismo contexto. Se concluye que la autonomía y la beneficencia se destacan en la dinámica de los cuidados de al final de la vida, ratificando la idea de que el paciente es el actor principal, debiendo ser oído, como también ser atendido en sus necesidades, para proporcionar un buen cuidado humanizado y digno. Además de los dilemas bioéticos, se revelan debilidades en el proceso de educación y comunicación en la relación equipo, paciente, familia.

Palabras clave: Ética. Grupo de atención al paciente. Relaciones profesional-familia. Participación del paciente. Cuidados paliativos al final de la vida.

The authors declare no conflict of interest.

Bioethics involves reflection on autonomous attitudes, such as decision making without coercion of values, based on the exercise of freedom, free from constraints or prejudices and with respect to differences. In everyday life, it is based on four principles: autonomy, beneficence, non-maleficence and justice, which seek to establish a new social contract between society, scientists, healthcare professionals and governments. In this context, bioethics provides the basis for the recovery of civil rights and quality of life¹.

For the sake of human dignity in the dying process, in death and in family grief, healthcare professionals are expected to follow bioethical principles to ensure end of life care¹. Such care involves active and comprehensive assistance to patients with severe, progressive and irreversible diseases who do not respond to curative therapy, seeking to control pain and other symptoms to provide early prevention and relief of physical, emotional, social and spiritual suffering². This viewpoint focuses on the patient and family, breaking with the paradigm of disease-centered care by understanding that nothing is more humane than helping to ease the suffering of both patients in palliative care and their families³⁻⁴.

Such considerations raise questions regarding decision making among healthcare professionals and the adversities involved in this context. In search of possible answers to this concern, this study aimed to identify the main conflicts between patients in end of life care, family and healthcare team from the point of view of principlalist ethics.

Method

This is an integrative, exploratory and descriptive review carried out according to the following steps: definition of the subject and formulation of the guiding question – “What are the main conflicts between patients in end of life care, family and healthcare team from the viewpoint of principlalist ethics?”; database research and definition of inclusion criteria; classification of articles; evaluation; interpretation and presentation of the knowledge synthesis⁵.

Based on the Pico (meaning Patient; Intervention or area of interest; Comparison; Outcomes) strategy and the guiding question, the articles were selected according to the following

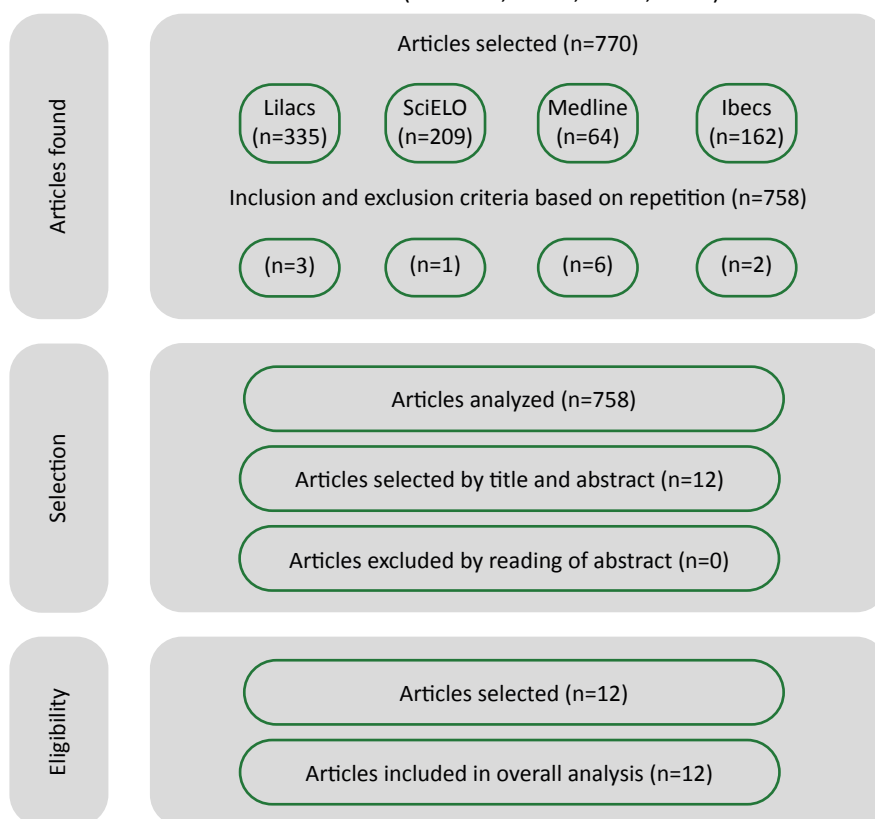
parameters: patients in end of life care, bioethical conflicts (area of interest), no comparison and principlalist ethics as outcome. The procedures used in the database searches and the exclusion criteria are shown in the flowchart (Figure 1), as recommended by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (Prisma)⁶.

The bibliographic survey was carried out on the Virtual Health Library (VHL) between June and July 2018, including the following databases: Latin American and Caribbean Health Sciences Literature (Lilacs), Scientific Electronic Library Online (SciELO), Medical Literature Analysis and Retrieval System Online (Medline) and *Índice Bibliográfico Español en Ciencias de la Salud* (Ibecs).

The descriptors selected were the terms of the Medical Subject Headings, also present in the Health Sciences Descriptors: “*equipe de assistência ao paciente*/patient care team”; “*família*/family”; “*bioética*/bioethics”; “*assistência ao paciente*/patient care”; and “*cuidados paliativos na terminalidade da vida*/hospice care.” No particular association of descriptors was made so as to produce a wider range of studies on the theme: “*equipe de assistência ao paciente*” and “*família*” and “*bioética*” and “*assistência ao paciente*” and “*cuidados paliativos na terminalidade da vida*” in Lilacs, SciELO and Ibecs in the VHL portal, and “patient care team” and “family” and “bioethics” and “patient care” and “hospice care” in Medline.

The inclusion criteria for the studies were complete papers that addressed ethical conflicts in the relationships between terminally ill patients in end of life care, family and hospital staff based on principlalist ethics, published between January 2014 and December 2017, in Portuguese, Spanish and English. Abstracts, editorials, duplicate articles, review articles (integrative or systematic), experience reports, case studies, letters to the editor, annals of scientific events, theses and dissertations were excluded. The time frame (2014-2017) aimed to obtain more up-to-date references on the subject in question. Following application of these criteria, the final sample comprised 12 articles, read in full and analyzed according to proposed goal (Figure 1).

An instrument was designed for data collection with the following items: characteristics (article title, author, journal, country), type, sample, goals and outcomes (main findings and contributions) of the studies analyzed. Lastly, the critical analysis and synthesis of the manuscripts that made up the research corpus were presented in three categories.

Figure 1. Prisma-based article selection flowchart (Salvador, Bahia, Brazil, 2019)

Outcomes

The sample consisted of 12 articles. Most of them were published in 2016 in Brazil and half used a qualitative approach. Regarding intellectual production, the Qualis Periódicos rating of the

journals ranged from A1 to B2. As for research participants, the articles were divided as follows: seven involved a multidisciplinary team, family members, caregivers and patients, three involved only doctors and two involved only nurses (Table 1).

Table 1. Studies included in the integrative review (Salvador, Bahia, Brazil, 2019)

Article number	Journal, year, country, Qualis rating and database	Contribution
Article 1 ⁷	<i>Revista Bioética</i> , 2014, Brazil, B2, Lilacs	Teaching: development of communication skills among professionals. Practice: communication as an instrument conducive to autonomy in therapeutic relationships, psychological adjustment and resolution of pending issues.
Article 2 ⁸	<i>Revista Online de Pesquisa Cuidado é Fundamental</i> , 2016, Brazil, B2, Lilacs	Practice: improving the quality of life of patients with no therapeutic possibilities.
Article 3 ⁹	<i>Medicine</i> (Baltimore), 2016, Taiwan, B2, Medline	Practice: decision-making training for nurses based on ethical principles and better community palliative care programs to improve problems encountered.
Article 4 ¹⁰	<i>Revista Bioética</i> , 2015, Brazil, B2, SciELO	Practice: prudent and reasonable decision making, that is, moral deliberation.
Article 5 ¹¹	<i>BMC Medical Ethics</i> , 2015, Mexico, B2, Medline	Practice: rediscovery of values and virtues in palliative care, helping professionals find greater motivation and a new perspective of professional and personal growth.

continues...

Table 1. Continuation

Article number	Journal, year, country, Qualis rating and database	Contribution
Article 6 ¹²	<i>Revista Bioética</i> , 2016, Brazil, B2, Lilacs	Teaching: routine palliative care as a developing academic subject. Practice: narrative bioethics can offer important input to enrich professional practice.
Article 7 ¹³	<i>Medicine, Health Care and Philosophy</i> , 2016, Netherlands, B1, Medline	Practice: reflective and sensitivity balance of healthcare professionals to better meet the needs of patients. In addition, the results can help them deal with hope in order to improve and strengthen the relationship with patients.
Article 8 ¹⁴	<i>The Oncologist</i> , 2015, Germany, A1, Medline	Practice: encouraging a proactive attitude among oncologists regarding the preparation of terminally ill patients. More concrete guidance is needed on when to start end of life communication to improve decision making in cases of patients with advanced cancer.
Article 9 ¹⁵	<i>Revista Bioética</i> , 2016, Brazil, B2, Lilacs	Teaching: creating opportunities for discussion during medical training on how to deal with patients' death. Research: new studies to further expand knowledge on the topic, involving other segments of society. Practice: experience of doctors and family members about end of life and death in order to redirect care in this difficult time of human life.
Article 10 ¹⁶	<i>BMC Medical Ethics</i> , 2014, Belgium, B2, Medline	Practice: different forms of closeness play an important role in caregivers' understanding of their moral responsibilities. This process clarifies the reasoning of participants when involved in practices such as continuous end of life sedation.
Article 11 ¹⁷	<i>Revista Bioética</i> , 2016, Brazil, B2, Lilacs	Practice: nurses should reflect on their daily professional practice to avoid useless treatment and provide more humanized care, favoring the dignity of terminal patients, minimizing their suffering and that of their families.
Article 12 ¹⁸	<i>BMC Medical Ethics</i> , 2014, Australia, B2, Medline	Practice: Australian doctors use the principle of double effect despite considering it a controversial and inappropriate medical-legal framework. These professionals feel obliged to negotiate the decision-making process in end of life care between patients and family based on a restrictive legal framework whose results influence the experience of all involved.

Discussion

To structure the discussion, the outcomes were classified into three topics: 1) professional conduct: respect for patient's autonomy and the principle of beneficence; 2) bioethical principles in the context of end of life care; 3) bioethical dilemmas in the same context.

Professional conduct: respect for patient's autonomy and the principle of beneficence

The principle of beneficence states that we must do good to others regardless of whether they want it, creating conditions for people to make their own decisions. This may give rise to bioethical dilemmas, such as the conflict between respecting patients' freedom (autonomy) and doing what is best for them (beneficence). Balance in this relationship is the potential key to elucidate the decision-making process. However, patients' decisions and their desire to undergo treatment or

not are also variables influenced by their cultural, social and family environment, by the patient/healthcare professional relationship and by the creation of a welcoming environment.

Among the strategies to minimize these conflicts are good communication between professionals, patient and family; respect for the autonomy, preferences and desires of the patient, without interfering with the principle of beneficence and guaranteeing dignity in the provision of care; bonds between professionals and patients for more humanized and holistic care^{7,13}. In addition, according to principlist ethics, the individual weaknesses and ambiguities of patients cannot be used to justify interference with and disrespect for their autonomy and right to make decisions.

In hospital, patients, family members and healthcare professionals need to maintain efficient and healthy communication so the family can act according to the preferences and recommendations of the patient when he or she is no longer able

to take decisions. It is up to the healthcare staff to question and confirm the decisions previously expressed by the person in end of life care. By limiting their performance to mere formal supervision, professionals contradict the principles of autonomy and beneficence in their professional practice⁶.

Bioethical principles in the context of end of life care

The process of dying and death are experienced in a unique way by each human being. On the other hand, these issues become part of the daily life of healthcare professionals due to the frequency with which they occur in their work environment. This is a topic that should be debated not only in this area but among society as a whole, since death is linked to issues such as acceptance, fear, uncertainties, revelations and, specially, anticipatory grief in the family, which can often alleviate suffering¹⁴.

In this context, healthcare professionals should discuss decisions related to end of life care with the team and family/caregivers, respecting the patient's dignity and autonomy, to minimize suffering¹⁴. Although many healthcare professionals have a good grasp of the concepts of euthanasia, dysthanasia and orthothanasia, sometimes the medical team ends up extending the treatment¹⁷ at the expense of the patient's well-being, as the patient's death is often viewed as a failure by the healthcare team.

Euthanasia is still a very controversial topic for involving ethical, moral and religious issues¹⁷. Despite being considered a crime in Brazil and in most of the world, it is often deemed an ideal solution to end suffering or a deliberate way to speed up death. In countries where euthanasia is legalized, the principle of patient autonomy guides the decision to speed up death, i.e., he or she has the power to decide on the issue¹⁷.

In Brazil, Article 5 of the Federal Constitution¹⁹ asserts the right to life and criminalizes the practice of euthanasia. However, orthothanasia, which also stresses patients' autonomous decision to have a more natural and painless death, has gained ground in multi-professional care, especially in the field of nursing¹⁶. Thus, bioethical principles contribute to guide medical ethics, supporting humanized initiatives in palliative care and ensuring the dignity of terminal patients^{20,21}.

Bioethical dilemmas in end of life care

The palliative care approach is directly related to the bioethical principles of beneficence,

non-maleficence, autonomy and justice, since patients with incurable diseases require refined, sensitive and humanized professional care²². Besides relief of physical pain, spiritual support is very important for the well-being of people in palliative care and must be provided throughout the entire process, combining biological and human sciences¹¹.

When trying to ease the suffering of terminal patients, healthcare professionals may become more involved than expected. Some studies stress the need for caution in how to proceed in this context to avoid exacerbation and compassion fatigue⁸. Depending on the individual, prognosis and life expectancy, hope is desirable, being the driving force in the struggle for life when there is still possibility of cure.

However, it is worth noting that in some situations hope may cause conflict between family and patients, extending human suffering in an attempt to avoid death at any cost. It is the responsibility of healthcare professionals to manage expectations in end of life care¹². On the other hand, paternalistic attitudes are still common among professionals who prefer to conceal patients' prognosis, preventing them from deciding on the care they would like to receive in the final phase of life²³⁻²⁴.

Alternatively, some studies^{8-10,15} suggest educational work and clarification about patients' autonomy to support decision making. However, one must avoid shifting the focus of individual decision making to a supposed collectivity, sharing responsibilities or merely playing the role of "executor" of the will of patients with terminal illness^{9,15}. It is a permanent education process in which healthcare staff also take on the role of guiding patients and their family to achieve humanized clinical practice¹⁰, considering the principles of principlalist ethics.

Final considerations

Respect for patient's autonomy and its relationship with beneficence was a key issue in the studies that made up the corpus of this survey. In this sense, bioethical dilemmas related to end of life care revealed weaknesses in education and communication between healthcare staff, patients and family.

Although the principles of justice and non-maleficence were not directly addressed in the studies in question, it was possible to identify them, for when we understand care based on beneficence and the definition of non-maleficence as “avoiding harm” and “wishing and doing what’s best for the patient/family”, we are automatically discussing non-maleficence.

Only two publications were found on the subject involving nursing staff^{8,17}. Therefore, one may conclude that there is a shortage of studies on the participation of nurses and how they deal with bioethical dilemmas in their relationships with the patients’ relatives. Moreover, this result may be associated with the limitations of this article.

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Participation of the authors

Maria Olívia Sobral Fraga de Medeiros, Mariana do Valle Meira and Rudval Souza da Silva wrote the manuscript. Fernanda Moreira Ribeiro Fraga helped carry out the biographical survey. Carlito Lopes Nascimento Sobrinho and Darci de Oliveira Santa Rosa helped with the final revision.

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