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## RESEARCH

## Ethical dilemmas in palliative care: a literature review

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**Abstract**

Issues concerning the beginning and end of life are an immense challenge for they involve various concepts related to science and religion, and have humanistic, social, legal, bioethical, and moral character. This study aimed to present the ethical dilemmas experienced by health professionals when facing death. Among the various ethical impasses, the main ones are resource limitations, the difficulty in communication and decision-making. They make us reflect on various end-of-life factors, such as establishing integrated communication, always telling the truth, and understanding non-adherence, discontinuations, and treatment refusals.

**Keywords:** Bioethics. Decision making. Terminal care. Health personnel.

**Resumo****Dilemas éticos em cuidados paliativos: revisão de literatura**

Em qualquer sociedade, assuntos concernentes ao início e fim da vida são imenso desafio, pois envolvem diversos conceitos relacionados a ciência e religião, de caráter humanístico, social, jurídico, bioético e moral. O objetivo deste estudo é apresentar os dilemas éticos explicitados por profissionais de saúde ao enfrentar processos de finitude. Dentre os diversos tipos de dilemas éticos encontrados, os principais perpassam a limitação de recursos, a dificuldade de comunicação e a dificuldade em tomar decisões. Esses dilemas levam a refletir sobre uma série de cuidados necessários, como estabelecer comunicação integrada, sempre dizer a verdade e entender renúncias, descontinuações e recusas ao tratamento.

**Palavras-chave:** Bioética. Tomada de decisões. Assistência terminal. Pessoal de saúde.

**Resumen****Dilemas éticos en cuidados paliativos: revisión de la literatura**

En cualquier sociedad, las cuestiones relativas al inicio y al final de la vida constituyen un inmenso desafío, ya que involucran varios conceptos relacionados con la ciencia y la religión, de carácter humanista, social, jurídico, bioético y moral. El objetivo del estudio es presentar los dilemas éticos explicitados por profesionales de la salud cuando están frente a procesos de finitud. Entre los diversos tipos de dilemas éticos encontrados, los principales son los recursos limitados, las dificultades de comunicación y las dificultades para tomar decisiones. Estos dilemas nos llevan a reflexionar sobre una serie de cuidados que debemos emplear en esos procesos de finitud, como establecer una comunicación integrada, decir siempre la verdad y comprender las renuncias, interrupciones y negativas al tratamiento.

**Palabras clave:** Bioética. Toma de decisiones. Cuidado terminal. Personal de salud.

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The author declares no conflict of interest.

With their peculiar care model, doctors Cicely Saunders and Elisabeth Kübler-Ross greatly influenced the development of palliative care<sup>1</sup>. According to Doyle and collaborators<sup>2</sup>, the hospice movement that Sanders idealized opposes the treatment then given to terminal patients, whose suffering was mainly pain, and had elaborating ways to control this symptom as a big concern<sup>3</sup>. Created in Great Britain, this new model spread throughout the United States, France, and several other countries, making Saunders the forerunner of palliative care in the world<sup>4-5</sup>.

The World Health Organization (WHO) first defined palliative care in 1986, but the concept was expanded according to local realities and epidemiological profiles, being redefined in 2002 as an *approach that improves the quality of life of patients and their families facing (...) life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual*<sup>6</sup>.

Matsumoto listed the WHO guiding principles of palliative care: *provides relief from pain and other distressing symptoms; affirms life and regard dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patient's illness and in their own bereavement; uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated; will enhance quality of life, and may also positively influence the course of illness; is applicable early in the course of illness, and should include those investigations needed to better understand and manage distressing clinical complications*<sup>7</sup>.

Assistance in palliative care needs to be comprehensive; it includes physical, spiritual, psychological and social aspects, with a careful look and multidisciplinary team<sup>8</sup>. The team approach allows knowledge exchange and facilitates understanding terminal patients' fragilities and conditions<sup>9,10</sup>. This is vital in palliative care, as it shows how fundamental each profession is, which individually cannot cover all palliative care nuances – collectivity plays an important role in adequate healthcare<sup>9,11</sup>.

Issues concerning beginning and end of life are an immense challenge, for they involve

various concepts related to science and religion, of humanistic, social, legal, bioethical, and moral character<sup>12,13</sup>. Cultural differences lead to different approaches: for instance, Vasconcelos and Pereira<sup>14</sup> point out that England, Australia and New Zealand are the countries that most invest in palliative care, according to the 2015 Quality of Death Index. Focusing on end-of-life implications, treatment decisions and the process of death are relevant, considering that such ethical dilemmas require reflections that involve the whole society on the most appropriate conducts<sup>15,16</sup>.

For Medeiros and collaborators, *the ethical dilemma is permeated by culture, philosophy and values (...). The plurality of different cultural contexts of a society that is constituted by individuals, who rank their values in a singular way based on autonomy, allows constant inquiries about issues that involve life and especially death*<sup>17</sup>.

Ethical dilemmas encompass two or more therapeutic options or directions appropriate to a given situation, being part of the practice of health professionals, which is susceptible to moral and/or social judgement<sup>18,19</sup>. They generate several concerns, motivating the scientific community to study it incessantly in legal and ethical terms<sup>20</sup>. Thus, this article aims to identify in the literature ethical dilemmas health professionals experience when caring for terminal patients.

## Method

This study is a literature review of articles available online. We searched several databases: Medical Literature Analysis and Retrieval System Online, Biblioteca Regional de Medicina (Bireme), Scientific Electronic Library Online, and Latin-American & Caribbean Health Sciences Literature. For the search, we used the following keywords in Portuguese and their correspondents in English and Spanish: *"bioética," "bioethics," "bioética"; "tomada de decisões," "decision making," "toma de decisiones"; "assistência terminal," "terminal care," "cuidado terminal"; and "pessoal de saúde," "health personnel," "personal de salud"*. We excluded case reports and studies that, despite presenting the listed descriptors, referred to ethical dilemmas experienced by patients or their families. In total, 51 articles were found, and after applying the criteria, we obtained a sample of 14 articles.

Sources and keywords were selected to focus on articles that referred to ethical dilemmas experienced by health professionals in end-of-life care, without limiting the year of publication.

The sample was classified according to authorship, year of publication, title, objective, method, and name of the journal in which it was published. Chart 1 shows the selected articles.

**Chart 1.** Non-systematic literature review corpus

| Author(s)/year                                         | Title                                                                                                                                          | Periodic                                                    | Objective                                                                                                                                                                                                      | Method                                              |
|--------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------|
| Araújo, Neves; 2003 <sup>21</sup>                      | "Bioethics and physiotherapy in intensive care units"                                                                                          | <i>Revista de Fisioterapia da Universidade de São Paulo</i> | Tracing the profile of physiotherapy professionals working in ICU and identifying their opinion on topics such as terminal patients, patient autonomy, euthanasia and dysthanasia.                             | Field research                                      |
| Barnitt; 1998 <sup>22</sup>                            | "Ethical dilemmas in occupational therapy and physical therapy: a survey of practitioners in the UK National Health Service"                   | <i>Journal of Medical Ethics</i>                            | Identify ethical dilemmas experienced by occupational therapists and physiotherapists working in the UK's National Health Service and compare ethical contexts, themes, and principles between the two groups. | Field research                                      |
| Bélanger, Rodríguez, Groleau; 2011 <sup>23</sup>       | "Shared decision-making in palliative care: a systematic mixed studies review using narrative synthesis"                                       | <i>Palliative Medicine</i>                                  | Synthesize the knowledge on shared decision-making process in palliative care.                                                                                                                                 | Literature review                                   |
| Chih and collaborators; 2016 <sup>24</sup>             | "The changes of ethical dilemmas in palliative care: a lesson learned from comparison between 1998 and 2013 in Taiwan"                         | <i>Medicine (Baltimore)</i>                                 | Investigate the ethical dilemmas encountered by palliative care physicians and nurses in 2013 and compare the results with a research conducted in 1998.                                                       | Field research                                      |
| Gjerberg and collaborators; 2010 <sup>25</sup>         | "Ethical challenges in the provision of end-of-life care in Norwegian nursing homes"                                                           | <i>Social Science and Medicine</i>                          | Examine the types and prevalence of ethical challenges in end-of-life care.                                                                                                                                    | Field research                                      |
| Mobasher and collaborators; 2013 <sup>26</sup>         | "Ethical issues in the end of life care for cancer patients in Iran"                                                                           | <i>Iranian Journal of Public Health</i>                     | Identify the ethical dilemmas that Iranian oncologists may face in healthcare environment and determine the factors that influence decision-making processes.                                                  | Field research                                      |
| Sorta-Bilajac and collaborators; 2011 <sup>27</sup>    | "How nurses and physicians face ethical dilemmas: the Croatian experience"                                                                     | <i>Nursing Ethics</i>                                       | Evaluate the ethical dilemmas of nurses and doctors in clinical practice.                                                                                                                                      | Field research                                      |
| Granero-Moya and collaborators; 2016 <sup>28</sup>     | "Primary care nurses' difficulties in advance care planning processes: a qualitative study"                                                    | <i>Atención Primaria</i>                                    | To understand the difficulties primary care nurses encounter when establishing advance directives of will of the terminally ill.                                                                               | Field research                                      |
| Guardia Mancilla and collaborators; 2018 <sup>29</sup> | "Perceptions of health care professionals about end-of-life care, obstacles and ethical dilemmas in hospitals, primary care and nursing homes" | <i>Anales del Sistema Sanitario de Navarra</i>              | Compare professional practice perception and the ethical dilemmas doctors and nurses face in terminal care in health centers, hospitals, and nursing homes.                                                    | Descriptive, cross-sectional, and multicenter study |
| Sánchez-García and collaborators; 2017 <sup>30</sup>   | "Facilitators and barriers regarding end of life care at nursing homes: A focus group study"                                                   | <i>Atención Primaria</i>                                    | Identify difficulties and factors faced by professionals working in nursing homes.                                                                                                                             | Field research                                      |

continues...

Table 1. Continuation

| Author(s)/year                              | Title                                                                                                              | Periodic                                  | Objective                                                                                                                                                                                       | Method            |
|---------------------------------------------|--------------------------------------------------------------------------------------------------------------------|-------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------|
| Motta and collaborators; 2016 <sup>31</sup> | "Decision making in clinical (bio)ethics: contemporary approaches"                                                 | <i>Revista Bioética</i>                   | Identify situations that distress health professionals and/or researchers in clinical practice, and briefly present reflections or approaches related to the decision-making process.           | Literature review |
| Renner, Goldim, Prati; 2002 <sup>18</sup>   | "Ethical dilemmas experienced in physical therapy practice"                                                        | <i>Revista Brasileira de Fisioterapia</i> | Identify ethical dilemmas in physiotherapists' practice.                                                                                                                                        | Field research    |
| Pereira; 2007 <sup>32</sup>                 | "Ethical dilemmas related to physiotherapy practice in attendance of children with physical and mental disability" | Master's dissertation                     | Verify in the professional practice of physiotherapists the ethical dilemmas that guide their therapeutic relationship with children with physical and/or mental disabilities and their family. | Field research    |
| Lorenzo, Bueno; 2013 <sup>33</sup>          | "The interface between bioethics and physiotherapy in Brazilian indexed papers"                                    | <i>Fisioterapia em Movimento</i>          | To study the theme and theoretical basis of the indexed articles that intended to discuss the interface between physiotherapy and bioethics.                                                    | Literature review |

## Results and discussion

Gjerberg and collaborators<sup>25</sup> sought to identify ethical challenges and their prevalence in the view of 664 health professionals working in Norwegian nursing homes. The interviewees often pointed out the inadequacy of care due to the scarcity of resources and the disregard for individuals' autonomy and integrity<sup>25</sup>. These observations corroborate the results found by Lorenzo and Bueno<sup>33</sup>, who describe several conflicts in the professional practice of physiotherapists, especially those related to the beginning and end of life, treatment refusal and decision-making when individuals' autonomy is somehow limited.

Guardia Mancilla and collaborators<sup>29</sup> surveyed 378 Spanish professionals working in hospitals, health centers, and nursing homes, and verified that the most frequent end-of-life ethical dilemmas were related to the use of advance directives of will. Granero-Moya and collaborators<sup>28</sup> investigated the difficulties faced by nurses in primary care in decision-making processes in terminal cases. They found little knowledge on the subject, communication difficulties, lack of time, and poor interprofessional relationship<sup>28</sup>.

In a study with Iranian oncologists, Mobasher and collaborators<sup>26</sup> perceived as ethical dilemmas saying the truth, uncertain definition of the patient's state and team-patient relationship. These findings reinforce Motta and collaborators' <sup>31</sup> study, who detected the concerns of health professionals in clinical practice and the difficulty faced in

decision-making processes, which are hindered in beginning and end-of-life situations. Two aspects that are difficult for health professionals are delivering bad news and establishing palliative care at the right time<sup>31</sup>.

Sánchez-García and collaborators<sup>30</sup> identified communication problems of the team with families and lack of incentives for patient participation in the decision-making as the main difficulties professionals experience when caring for older adults living in Spanish nursing homes. For Sorta-Bilajac and collaborators<sup>27</sup>, the ethical challenges Croatian doctors and nurses face in their clinical practice concern euthanasia, assisted suicide, and limitation of life-sustaining therapies. In a comparative study, Chih and collaborators<sup>24</sup> described the changes in ethical dilemmas in palliative care between 1998 and 2013 in Taiwan. In 1998 the difficulties were guiding patients, families refusing to take patients home, and omitting the truth from the terminally ill, while in 2013 they were related to resource allocation.

According to Barnitt<sup>22</sup>, the ethical issues physiotherapists face are still little known. In their study with professionals of the National Health Service of England, the results indicated unfair allocation and lack of resources, low effectiveness of physiotherapeutic treatment, divergent therapeutic decisions among the team, disregard for patient confidentiality and autonomy, and omission of the truth. The occurrence of ethical challenges prevailed, according to research participants, in the hospital environment<sup>22</sup>.

In turn, Renner, Goldim and Prati<sup>18</sup> identified using a questionnaire that most of the difficulties reported by physiotherapists working in Porto Alegre/RS were based on the limit of professional performance, followed by the omission of truth and lack of resources, and therapy efficiency, drawing attention to the considerable number of answers that reported absence of dilemmas. The result corroborates the study of Pereira<sup>32</sup>, who investigated the same professional category, but in the care of children with physical and/or mental disabilities and their family members in the city of Campinas/SP. The author concluded that many of the respondents, most with less than 15 years of experience, are concerned and committed to ethics, but did not identify impasses in their professional performance, but rather everyday issues such as physical therapy discharge<sup>32</sup>.

## Final considerations

The ethical dilemmas health professionals face in end-of-life situations lead us to reflect on the death process. Examples of healthcare in these cases are integrated communication between professional, patient and family members; the duty to always inform the truth; and the need to understand renunciations, discontinuations, and treatment refusals.

The decision-making process has been one of the main obstacles for health professionals in terminal care, caused mainly by insecurity, lack of training and knowledge on the topic. Other studies are still needed to better evaluate what health professionals consider more relevant when making decisions that involve these dilemmas.

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