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Bioethical aspects of health care provided to older adults at the end of their lives

Aspectos bioéticos dos cuidados em saúde às pessoas idosas ao fim da vida

Aspectos bioéticos de los cuidados de salud a adultos mayores en el final de la vida

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ABSTRACT

Objective: to examine the Brazilian and international scientific production for connections between bioethical principles and the health care provided to older adults at the end of their lives. **Method:** between October and November 2019 this integrative review searched the Medline (Pubmed), Lilacs, and Scopus databases using the descriptors: "Palliative Care", "Aged", and "Bioethics" for the period 2014-2019. **Results:** the following categories emerged from the selected articles: therapeutic conducted with regard to end-of-life care; decision making on end-of-life care; and challenges in end-of-life care. **Conclusion:** of particular importance is for health professionals to uphold their commitment to older adults and their families, consider their subjectivities and preferences, and empower and equip them so that care is guided by bioethical principles in order to assure a dignified process of dying and death.

Descriptors: Bioethics; Aged; Palliative Care.

RESUMO

Objetivo: analisar a produção científica nacional e internacional, buscando as interfaces existentes entre os princípios bioéticos e os cuidados em saúde prestados ao fim da vida às pessoas idosas. **Método:** revisão integrativa, cuja busca ocorreu entre outubro e novembro de 2019 nas bases de dados Medline via Pubmed, Lilacs e Scopus com os descritores: "Palliative Care", Aged e Bioethics de 2014-2019. **Resultados:** a partir dos artigos selecionados, emergiram as seguintes categorias: condutas terapêuticas frente aos cuidados ao fim da vida; tomada de decisão nos cuidados ao fim da vida; e desafios nos cuidados ao fim da vida; tomada de decisão nos cuidados ao fim da vida; e sua família de forma a considerar suas subjetividades e preferências e os instrumentalizar para que os cuidados sejam pautados em princípios bioéticos, para assim proporcionar um processo de morte e de morrer com dignidade. **Descritores:** Bioética; Idoso; Cuidados Paliativos.

RESUMEN

Objetivoexaminar la producción científica brasileña e internacional en busca de conexiones entre los principios bioéticos y la atención médica brindada a los adultos mayores al final de sus vidas. **Método:** entre octubre y noviembre de 2019, esta revisión integradora buscó en las bases de datos Medline (Pubmed), Lilacs y Scopus utilizando los descriptores: "Cuidados paliativos", "Envejecido" y "Bioética" para el período 2014-2019. **Resultados:** las siguientes categorías surgieron de los artículos seleccionados: terapéutico realizado con respecto a la atención al final de la vida; toma de decisiones sobre la atención al final de la vida; y desafíos en la atención al final de la vida. **Conclusión:** es de particular importancia que los profesionales de la salud mantengan su compromiso con los adultos mayores y sus familias, consideren sus subjetividades y preferencias, y los empoderen y equipen para que la atención se guíe por principios bioéticos para asegurar un proceso digno de muerte y muerte. **Descriptores:** Bioética; Anciano; Cuidados Paliativos.

INTRODUCTION

Population aging is a reality in many countries, including Brazil, whose population over 60 has increased markedly in recent decades¹. Nowadays, when talking about old age, it is not only thinking about aging in terms of the passage of time, but also about how this phase of life has been experienced by the individuals through their relationships with social, economic, biological, and psychological factors.

Thus, the study of human aging is a topic of great relevance in the academic setting, as the promotion of a dignified, active, and healthy old age has become a relevant factor for society and for the various spaces where the older adult is inserted².

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The aging person inevitably experiences a functional, progressive, and irreversible decline. As functionalities are lost in several areas, the main consequence arises: frailty, a risk condition for the organism³.

The predominance of frailty and the existence of multimorbidity and functional losses, which increase with advancing age, have a great impact on the survival of older adults, with implications for susceptibility and evolution to death⁴.

The latter involves the provision of end-of-life health care. In this way, adequate care is included for the relief of pain and symptoms resulting from the advanced stage of a disease, and must provide psychosocial and spiritual support in all the stages, from the diagnosis of an incurable disease to the family's mourning period⁵. Therefore, the provision of care to the older adults includes not only attention to their health, but also the involvement of the family, since they often exercise the role of caregiver⁶.

Thus, palliative care emerges as a care philosophy to improve the quality of life of patients and their families in the process of coping with the end of life⁵.

Living remains a fundamental issue; therefore, health care for the older adult in the final stages of life has as a goal not to cure, but to care in the perspective of providing better quality of life, prevention, and relief of suffering. Thus, the care we refer to is inserted within the scope of bioethical reflection⁷.

In this context, the objective of this study was to analyze the national and international scientific production, looking for the existing interfaces between the bioethical principles and the health care provided to older adults at the end of their livs. For this, the study is based on the principles of beneficence, non-maleficence, autonomy, and justice that guide biomedical ethics, also known as Principialist Bioethics⁸.

Therefore, the relevance of this study is in the possibility that, based on its results, it is possible to maximize the reflections on the bioethical implications arising from the health care provided to older adults at the end of their lives and a better understanding of this phenomenon.

METHOD

This is an integrative review. For this, six stages were covered: identification of the theme and selection of the research question; establishment of inclusion and exclusion criteria for studies; definition of the information to be extracted from the studies and categorization; evaluation of the studies included in the integrative review; interpretation of the results; and presentation of the review/synthesis of knowledge^{9,10}.

Thus, the following guiding question was formulated: What are the interfaces between the bioethical principles and the health care provided to older adults at the end of their lives? Through the PICo strategy, synthesized by the acronym PICo, where "P" corresponds to the population (older adults), "I" to the phenomenon of interest (end-of-life health care), and "Co" to the context of the study (bioethical principles)¹¹.

The survey was conducted between October and November 2019 and updated in April 2020, in the Medline via Pubmed, Lilacs, and Scopus databases. The search strategy considered the Boolean operator *And*, the time frame was 2014-2019, the languages were Portuguese, English and Spanish, and the following descriptors were used: "Palliative Care", "Aged" and "Bioethics". The inclusion criterion was the following: articles in their entirety that addressed end-of-life care for the older adults. And the exclusion criteria were articles that did not meet the proposed objective, reviews, dissertations or theses, reflection articles, comments, editorials, summaries of events, and case reports.

The level of evidence was also identified from the study design, assigning I for systematic reviews and metaanalysis of randomized clinical trials; II for randomized clinical trials; III for non-randomized controlled trial; IV for casecontrol or cohort studies; V for systematic reviews of qualitative or descriptive studies; VI for qualitative or descriptive studies; and VII for the opinion of authorities and/or reports of expert committees. This hierarchy classifies levels I and II as strong, III to V as moderate, and VI to VII as weak¹².

Articles published in Portuguese, English, and Spanish were included, and 109 publications were found - 88 in MEDLINE, 16 in SCOPUS, and 5 in LILACS -, which were evaluated in order to verify if they met the study inclusion criteria. Of these, 24 articles address the research question. The flowchart of the article selection process is shown below in Figure 1.



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FIGURE 1: Flowchart for the selection of the studies found, according to the PRISMA recommendations. Rio de Janeiro-RJ, Brazil, 2020.

RESULTS AND DISCUSSION

24 scientific articles¹³⁻³⁶ were analyzed, of which 58.3% were level VI, 37.5% level IV, and 4.2% level II. The methodological approach that prevailed was the qualitative one (58.3%), followed by the quantitative (41.7%). Regarding the years of publication of the studies, 03 were identified in the years 2014 and 2019 (12.5%), 04 (16.7%) in the years 2016 and 2017, and 05 in the years 2015 and 2018 (20.8%).

As to the origin of the articles: 45.8% were developed in North American countries^{13,14,16,18,20,22,24,26,29,33,34}, 41,7% in European countries^{15,17,21,23,25, 30-32,35,36}, 8.3% in South American countries^{27,28}, and 4.2% in a country in Oceania¹⁹. The country that most published on this them was the United States^{13,14,16,18,20,22,24,26,29,33}, followed by Portugal^{17,21,25,32} and by Belgium^{23,30,31,35}.

The analysis of the information from the integrative review was performed using a table prepared by the authors for the extraction and synthesis of the data, containing the following: title of the article, name of the authors, journal/year/place of publication, level of evidence, type of study, methodology, main results, and conclusions. The chart made it possible to analyze and critically interpret the studies, which were grouped empirically according to their differences and similarities. The summary of the selected articles is shown below in Figure 2.

Thus, based on its content, three categories were defined: therapeutic behaviors towards end-of-life care; decision-making in end-of-life care; and challenges in end-of-life care.



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Title	Journal/Year	Level of Evidence
Prospect Theory Concepts Applied to Family Members of Nursing Home Residents with Cancer: A Good Ending Is a Gain ¹³	J Soc Work End Life Palliat Care, 2019	Level VI
Did a Goals-of-Care Discussion Happen? Differences in the Occurrence of Goals-of-Care Discussions as Reported by Patients, Clinicians, and in the Electronic Health Record. $^{\rm 14}$	J Pain Symp Manag, 2019	Level IV
"I go into crisis when": ethics of care and moral dilemmas in palliative care ¹⁵ .	BMC Palliat Care. 2019	Level VI
Surrogate Decision Makers' Perspectives on Family Members' Prognosis after Intracerebral $\rm Hemorrhage^{16}$	J Palliat Med. 2018	Level VI
End-of-Life Decision Making in Palliative Care and Recommendations of the Council of Europe: Qualitative Secondary Analysis of Interviews and Observation Field Notes 17	J Palliat Med, 2018	Level VI
POLST Facilitation in Complex Care Management: A Feasibility Study ¹⁸	Am. J. Hosp. Palliat. Care, 2018	Level IV
Patient autonomy and advance care planning: a qualitative study of oncologist and palliative care physicians' perspectives $^{\rm 19}$	Support. Care Cancer, 2018	Level VI
Palliative Care Consultation Trends Among Hospitalized Patients With Advanced Cancer in the United States, 2005 to $2014^{\rm 20}$	Am. J. Hosp. Palliat. Care., 2018	Level VI
Effect of dignity therapy on end-of-life psychological distress in terminally ill Portuguese patients: A randomized controlled trial $^{\rm 21}$	Palliat. Support. Care, 2017	Level II
Health Care Professionals' Attitudes About Physician-Assisted Death: An Analysis of Their Justifications and the Roles of Terminology and Patient Competency $^{\rm 22}$	J. Pain. Symptom Manage, 2017	Level IV
Reasons for continuous sedation until death in cancer patients: a qualitative interview $study^{23}$	Eur. J. Cancer Care (Engl), 2017	Level VI
The Quality of Physician Orders for Life-Sustaining Treatment Decisions: A Pilot $Study^{24}$	J. Palliat. Med., 2017	Level VI
Prevalence and factors associated with demoralization syndrome in patients with advanced disease: Results from a cross-sectional Portuguese study $^{\rm 25}$	Palliat. Support. Care, 2016	Level IV
Constructing High-stakes Surgical Decisions: It's Better to Die Trying ²⁶	Ann. Surg, 2016	Level VI
Vivências da morte de pacientes idosos na prática médica e dignidade humana ²⁷	Rev. bioét., 2016	Level VI
Desafios para o cuidado digno em instituições de longa permanência ²⁸	Rev. bioét., 2016	Level VI
How clinicians discuss critically ill patients' preferences and values with surrogates: an empirical analysis $^{\rm 29}$	Crit. Care Med., 2015	Level VI
Using continuous sedation until death for cancer patients: a qualitative interview study of physicians' and nurses' practice in three European countries 30	Palliat. Med, 2015	Level VI
Bridging the gap between continuous sedation until death and physician-assisted death: a focus group study in nursing homes in Flanders, Belgium ³¹	Am. J. Hosp. Palliat. Care, 2015	Level VI
Therapeutic futility in cancer patients at the time of palliative care transition: An analysis with a modified version of the Medication Appropriateness Index ³²	Palliat. Med, 2015	Level IV
Upstream discussion provided in the ambulatory setting to assist patients with chronic kidney disease considering dialysis ³³	Perm J. 2015	Level IV
Factors affecting family satisfaction with inpatient end-of-life care ³⁴	PLoS One, 2014	Level IV
Continuous sedation until death with or without the intention to hasten deatha nationwide study in nursing homes in Flanders, Belgium ³⁵	J. Am. Med. Dir. Assoc, 2014	Level IV
Estimating the potential life-shortening effect of continuous sedation until death: a comparison between two approaches ³⁶	J. Med. Ethics., 2014	Level VI

FIGURE 2: Summary table of the articles selected in the databases. Rio de Janeiro-RJ, Brazil, 2020.

Category 1: Therapeutic approaches towards end-of-life care

Eight studies made up this category and involved actions¹⁵ and procedures¹⁹ related to the approach and therapeutic conduct in older adults near the end of life, when symptoms are intractable and refractory. Diverse care modalities are observed, such as euthanasia^{22,30,31}, assisted death^{22,31}, and palliative sedation^{23,30,31,35,36}.



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The ethical approach in therapeutic approaches to end-of-life care involves actions of listening, dialog, compassion, solicitude, and maintenance of hope, within the care relationship, respecting as much as possible the degree of autonomy and meeting the individual's spiritual needs¹⁵.

Among these precautions, intensive care procedures are identified, such as mechanical ventilation, percutaneous endoscopic gastrostomy, placement of tubes, parenteral nutrition, hemodialysis, chemotherapy, and radiotherapy¹⁹.

Voluntary active euthanasia occurs when death is caused at the patient's own request, being a way of guaranteeing their autonomy. For a patient who does not have preserved cognitive capacity, such care is favored when there is a directive of anticipated will²².

The legalization of physician-assisted death involves patient-centered justifications, such as relief of the patients' suffering and pain (the principle of beneficence and non-maleficence), the patients' right to die as they wish (principle of autonomy), and mercy (principle of justice).

Palliative sedation can be used until death; it may be brief or intermittent³⁶. It is informed by the patient's desire, occurring when a refractory symptom remained present before the start of sedation, being a request for relief of suffering³⁰. Therefore, the patient is more involved in the decision-making process, thus ensuring the preservation of the principles of autonomy and justice.

There is an extensive debate regarding the practice of palliative sedation until death, due to undesirable and morally complex damages such as shortening of life³⁶ and the preservation of conscience³⁰.

Some consider palliative sedation until death a palliative treatment between pain relief and the end of life^{31,35}, others claim that it is often used with the intention of accelerating death^{25,30}. And some point out that this care allows for a "natural" death and for an 'alternative', as well as euthanasia, which could be chosen by the patient^{30,31}.

Paying attention to the principle of beneficence, if the benefit of palliation is greater than the harms of a premature death, sedation can be indicated even if death is not imminent³⁶.

Inclusive and shared decision-making involving all members of the care team, as well as the patient and the family, needs to be considered in therapeutic approaches to end-of-life care to preserve patient autonomy, with the ability to increase the chances of finding the right balance in a clinical approach²³.

The analysis of the therapeutic behaviors identified in the studies leads to an ethical reflection on the complexity of health demands in this phase of life, especially when the individual is on the verge of death, pointing to the importance of the discussion and transparency of the older adult's prognosis among health professionals and family members, aiming at the preservation of the principles of autonomy, justice, beneficence, and non-maleficence, especially when the conduct involves palliative sedation.

Category 2: Decision-making in end-of-life care

Nine studies fall into this category^{13,14,16,18,19,24,29,33,34} and address the current preferences of the older adults and decision-making in their end-of-life care considering the bioethical principles.

The quality of care decisions at the end of life of the older adults should reflect their current preferences and those of their families, and it is important that they are well informed about the care needed to preserve their bio-psychosocio-spiritual well-being²⁴.

Assessing the personal choices of the older adults and their families, anticipating situations, and planning care are actions that indicate quality in care at the end of life¹⁶.

Sharing care goals and discussing them in the context of an outpatient consultation with the patient's doctor or nurse appears to be an important initial step in the planning process for successful end-of-life care¹⁴. However, it is often observed that discussions do not take place in a timely manner regarding the preferences or values of the older adults at the end of their lives, which interferes with the effectiveness of end-of-life care²⁹.

As part of the advanced planning in providing end-of-life care, seniors and their families can be better involved in conversations about what risks are worth taking and avoiding, and exploring what results and risks they and their families are willing to seek. or wish to avoid¹³, as their preferences are often not considered due to lack of knowledge about these issues²⁴.

The patients' autonomy is often threatened, because even if they are encouraged to express their preferences for care, medical rules about the quality and "reasonableness" of care, the availability of services, and



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family relationships increase or limit the patients' ability to perceive their preferences, problematizing individual choice¹⁹.

Another important issue that deserves to be discussed is the preference of the older adults regarding the place of their death. Almost half of the relatives believe that the older adults would prefer their death to occur at their home; however, the most common place of death is the hospital, especially the ICU³⁴. This indicates the importance of discussing the possibility of choice with the family and the older adults, so that their rights regarding the choice of the place of death are preserved, thus respecting the principles of autonomy and beneficence.

Having the opportunity to discuss the limits and possibilities of end-of-life care is important for patients and family members and helps them to better understand their choices, clarifying treatment goals. This discussion must be documented in the patients' medical record, to serve as a reference for the multidisciplinary team that accompanies them³³.

Therefore, the adoption of strategies to guarantee a person-centered service that reflects the goals, values, and preferences of each individual becomes essential to improve end-of-life care, in order to help them think about their preference, which is an important factor for decision-making¹⁸. Advanced care planning programs, in which the patients' preferences are considered, are important strategies for respecting the autonomy of the older adults in end-of-life care¹⁹.

There are great care challenges that often limit the older adults to choose the health care they want, among them the lack of personal engagement in health decision-making for their own well-being, which indicates losses in guaranteeing the principle of justice for those individuals.

Thus, the efficiency of decision-making is closely linked to guaranteeing the principles of justice and autonomy for the older adults and their families, as an effective decision-making process is characterized by a shared decision-making approach that considers the preferences of the older adults and of their families in the care actions implemented.

Category 3: Challenges in end-of-life care

This category consists of seven articles^{17,21,25,26,28,32,34} which address the challenges encountered in caring for older adults at the end of their lives to preserve bioethical principles and human dignity.

The first challenges highlighted are the following: the provision of compassionate care to support family members and older adults; maintaining a health team working together as a cohesive team; listening attentively to the patients and family members; and the prevention of and aggressive and technology-loaded care. Such challenges are important for the preservation of the principles of beneficence, non-maleficence, autonomy, and justice³⁴.

Another challenge found was polypharmacy. The excess of prescription drugs increases the risk of adverse events, without adding any substantial benefit to the older adults. It is important to consider a review of the therapeutic plan for the older adult in end-of-life care, in order to identify potentially inappropriate drugs, eliminate drugs of decreasing value, and add preventive and palliative therapeutic drugs³², in order to guarantee the principle of non-maleficence.

An observed challenge was the prognostic communication in acute critical diseases, in the case of intracerebral hemorrhage, for example, where conflicting prognostic information was evidenced, such as different prognostic estimates or varied terminality among the members of the health team, which has contributed to different decisions with life or death implications for the patient and additional suffering for family members¹⁷.

The surgical interventions performed in older adults in end-of-life care were also evident challenges. Older adults and surgeons seem to agree that the precept of maximizing quality of life, as well as that of loss of independence, should guide treatment decisions. Before considering surgery as an option, it should be noted whether it has the potential to impair the autonomy of the older adult. If the benefits of surgery are limited, it is necessary to review its need to avoid unnecessary harms²⁶, thus preserving the principle of beneficence and non-maleficence.

Three other challenges were observed in long-term care institutions for older adults (*Instituições de Longa Permanência para Idosos*, ILPIs), and involved coping with the commodification of care, social protection, and the implementation of adequate structures²⁸. Such challenges can affect the quality of care for these older adults, interfering in guaranteeing the principles of beneficence, non-maleficence, and justice.

In addition to these challenges, there is also psychological suffering^{21,25,28}. Frequently, the presence of anxiety, depression, demoralization syndrome, death wishes, anecdotal states, helplessness, and hopelessness is identified^{21,25}.

In long-term institutions, it is observed that work is not conducted under the perspective of relieving suffering and death²⁸; and in hospitals there is a lack of health actions in the face of the psychological suffering of hospitalized older



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adults due to their persistent psychological suffering. This may also reflect a lack of psychosocial support services or the absence of effective interventions being offered to these patients throughout the disease process²⁵.

Taking into account such psychological suffering from a psychosocial diagnosis is of clinical importance for the practical exercise of beneficence and non-maleficence, demonstrating the relevance of psychological monitoring in coping with potentially fatal diseases in end-of-life care. Dignity Therapy (DT) proves to be a brief individualized intervention capable of promoting improvements in terms of psychological suffering and constant sadness²¹.

It should be noted that this multiplicity of challenges indicates that the death process involves therapies that go through discussions related to the maintenance of an ethical posture by the health professionals in the provision of care, inadequate infrastructure of the health services, lack of psychosocial support by the health services, and development of a therapeutic plan that considers this new phase of life. These challenges often need to be considered in bioethical discussions to achieve and guarantee the principles of justice, beneficence, and non-maleficence.

CONCLUSION

The results of this review point to the complexity in conducting appropriate therapies for the older adults in the final stages of life, revealing the need for the involvement and better engagement of the older adults and their families in decision-making to avoid unwanted therapeutic conduct, also pointing to the persistence of the different challenges that need to be continually discussed to preserve the bioethical principles and the effectiveness of the care provided.

In addition, they show the importance of applying bioethical principles to improve the quality of health care provided to the older adults at the end of their lives.

As a result, it is recommended that new studies be carried out in order to discuss and deepen issues related to the end-of-life health care provided to the older adults, with a view to guaranteeing the bioethical principles in the care of these individuals. It should be noted that this study has some limitations, such as the inclusion of only three databases, which may have led to the non-inclusion of some studies on the theme. Also noteworthy is the difficulty in accessing a publication in its entirety, hindering its approach.

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