

RESEARCH ARTICLE

Available online at http://www.journalijdr.com



International Journal of Development Research Vol. 10, Issue, 02, pp. 33786-33790, February, 2020



OPEN ACCESS

HOSPICE CARE AND TERMINALITY: DIGNITY WHEN DYING

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ARTICLE INFO

Article History: Received 19th November, 2019 Received in revised form 21st December, 2019 Accepted 17th January, 2020 Published online 27th February, 2020

Key Words:

Hospice care; Terminaly; Bioethics.

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ABSTRACT

The current bibliographic study aims to encourage the discussion about terminality and the institution of palliative care in patients with therapeutic impossibility of cure in the bioethical context. The selected articles were indexed in the period from 2005 to 2019, three online databases were used: SciELO, Lilacs and BIREME. The technological advancement in medicine was followed by an increase in patient survival, especially those with incurable diseases. Therefore, it is necessary to foster discussions about terminality and palliative care, as well as fundamental concepts in this context, such as euthanasia, dysthanasia and orthothanasia, based on minimizing the pain and suffering of terminally ill patients.

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Citation: Lêda Lima da Silva, Alyne Condurú dos Santos Cunha, José Francisco Alves de Andrade et al. 2020. "Hospice care and terminality: dignity when dying", International Journal of Development Research, 10, (02), 33786-33790.

INTRODUCTION

For a long time, death was a part of a family ritual, in which the patient was surrounded by his loved ones, so that the process of dying was the moment of leaving, thus facilitating or decreasing the loss of suffering for everyone involved in the health-disease process. With the advent of the technological apparatus, the intensive care centers and the increase in life expectancy, death started to be seen as a problem or error of conduct - by health professionals - and generated - for the family members of the patient with advanced and incurable disease - a difficult process of disconnection and termination, causing, in both parts, a feeling of impotence and nonconformity. This patient is surrounded by strangers, in a stressful and hostile environment, often suffering from pain due to invasive processes, exacerbated by the pain of abandonment (FELIX *et al*, 2013). Faced with the context experienced by modern suffering medicine at the end of life, the discussion about palliative care, dignity when dying and bioethics is extremely important, as its fundamental purpose is to maintain dignity during the dying process, relieving suffering pain of terminally ill patients, promoting multiprofessional support for them and their families (SILVA *et al*, 2013). For this reason, the present study sought to carry out a bibliographic review of the literature, in order to evoke the discussion about the terminality of the lives of patients with the impossibility of therapeutic cure, emphasizing the importance of palliative care in this process of dignified death and humanization of health. In addition, we sought to discuss the concepts essential to these aspects, such as euthanasia, dysthanasia and orthothanasia.

MATERIALS AND METHODS

This is a critical bibliographic review about hospice care, the end of life, in the light of the bioethical concepts of the

Table 1. List of 26 studies related to palliative care, terminal life and bioethics

Authors	Title	Year	Method
Siqueira-Batista R, Schramm FR	Conversations about "good death": the bioethical debate about euthanasia	2005	-
Floriani CA, Schramm FR	Palliative care: interfaces, conflicts and needs	2008	_
Fonseca AC, Junior WVM, Fonseca MJM	Palliative care for the elderly in the intensive care unit: a systematic review	2012	Systematic review
Meneguin S, Ribeiro R	Difficulties of caregivers of patients in palliative care in the family health strategy	2016	Descriptive exploratory study
Silva RS	Palliative care nursing for dying with dignity: cipe® terminological subset	2014	Methodological study
Paiva FCL, Júnior JJA, Damásio AC	Ethics in palliative care: conceptions about the end of life	2014	Literature review
Felix ZC, Costa SFG, Alves AMPM,	Euthanasia, dysthanasia and orthothanasia: an integrative	2013	Integrative review
Andrade CG, Duarte MCS, Brito FM	literature review		-
Garcia JBS	Euthanasia, dysthanasia or orthothanasia?	2011	Editorial
Floriani CA	Modern hospice movement: kalothanasia and the aesthetic revival of the good death	2013	Update article
Costa RS, Santos AGB, Donha Yarid SD,	Bioethical reflections on the promotion of palliative care to	2016	Integrative review
Silva Sena ELS, Boery RNSO	the elderly		c
Magalhães JL, Nunes R	Hippocratic tradition and ethical foundations applicable to the end of life	2014	Update article
Amanda M	National cancer control programmes: policies and managerial guidelines	2002	Guideline WHO
Rodrigues LA	Palliative care, diagnosis and terminality: indication and beginning of the palliation process	2015	Qualitative and exploratory research
Roest B, Trappenburg M, Leget C	The involvement of family in the Dutch practice of euthanasia and physician assisted suicide: a systematic mixed studies review.	2019	Systematic review
De Lima et al	International Association for Hospice and Palliative Care Position Statement: Euthanasia and Physician-Assisted Suicide	2017	Consenso de especialistas
Marty CM, Carter BS	Ethics and palliative care in the perinatal world	2018	Revisão sistemática
Rates, CMP	Bioethics and access to palliative care in primary health care	2018	Dissertação de mestrado

dignified and humanized death process, relating them to human dignity. Therefore, it fits into the Evidence-Based Practice, enabling the survey and analysis of studies related to bioethics and the implementation of its evidence of medical practice. The literature survey was based on articles indexed in PubMed, the Virtual Health Library (VHL) and the Latin American and Caribbean Health Sciences Information Center (Bireme), based on the Scientific Electronic Library Online databases (SciELO) and Latin American and Caribbean Literature in Health Sciences (Lilacs). Health Sciences Descriptors (DeCS) in Portuguese and English were used: "hospice care" (cuidados paliativos); "Bioethics" (bioética). Finally, the descriptors were joined by the Boolean operator "and". The inclusion criteria used were: complete articles with abstracts in Portuguese and in English and a direct link with the descriptors. Thus, the exclusion criteria referred to studies without relevance to the theme, that is, that did not deal with the researched subject, and not indexed in the databases used. In this context, data collection was carried out by the researchers, using articles published in the interval between the years 2005 to 2019, independently, for the evaluation and comparison of the results found later.

RESULTS

It was found 62 articles in the Pubmed database, 10 in the other databases. After their critical analysis, in which the researchers read the abstract of each analyzed article; excluding duplicates and those indexed outside the established period, 26 publications were selected, this being the final sample of the critical literature review (Table 1).

DISCUSSION

Death is a phenomenon subject to multiple interpretations that differ between societies, cultures, beliefs and historical contexts (PAIVA *et al*, 2014).

It integrates the process of living and medicine must deal with these extremes - life and death (WHO, 2002). The evolution of modern medicine has made it possible to increase survival and improve health care, with a decrease in morbidity and mortality from infectious diseases, improving life expectancy. At the same time that there was an increase in morbidity and mortality at the expense of chronic-degenerative diseases mainly related to cancer and cardiovascular diseases - not only linked to the evolution of diagnosis, treatment and reduction of indexes and parameters for measurement of many of these diseases, but also directly related to the decline in lifestyle and habits, sententarism, excessive and extremely caloric nutrition, together with obesity. The evolution of health care and intensive care units, in turn, brought the possibility of monitoring illnesses and cures, with reduced sequelae in various illness processes, improving quality survival (PANIS et al, 2018; FA- BINEFA et al, 2019). This improvement process emphasized, on the other hand, an unhealthy aspect of medicine: the denial of death. Medicine has embarked on the ceaseless and heroic quest to save lives, even when they can no longer be saved. Taking healing as his only objective, he stopped contemplating the human being holistically in its spiritual, psychological and social dimensions, considering only his physical condition (FELIX et al, 2013; FONSECA et al, 2012). In medical training courses, it is observed that teaching about dying is far from being treated in a systematic way, as little is discussed about palliative care and terminality. Death is characterized as a process that must be avoided at all costs. When faced with these patients, the student tends to follow the example of their teachers, who often face the fact with coldness and detachment under the justification that personal involvement leads to dullness in the care that the patient should receive and that, thus, the doctor must protect himself from the suffering related to the death of his patient (FELIX et al, 2013; SANTORO, 2010). There is little debate on these issues in professional life either, death is not seen as

part of the process of living, but rather as a professional defeat or an error made by the team during care and treatment. Such perception can lead the doctor to give his patients in advanced disease stage invasive, painful, expensive treatments, which do not bring any additional benefit or cure (COSTA *et al*, 2016; MAGALHÃES and NUNES, 2014).

Currently, the vision of palliative care has been changing among health professionals with the advent of discussions in the residences of medical clinic, oncology, oncology surgery and anesthesiology, as well as the increase in the role and importance of the discipline of bioethics both in the faculties of medicine and in graduate courses. Thus, the vision of death has been redefined and palliative care fills a gap in the treatment of terminally ill patients, supporting them in controlling pain, monitoring and psychological, social and spiritual comfort both for themselves and their families, without prolonging or shorten the process of dying (FA-BINEFA et al, 2019; SILVA et al, 2014; CRMSP. 2008). It is important to differentiate the terms euthanasia, dysthanasia and orthothanasia in the process of the terminality of life. The term euthanasia is etymologically derived from the Greek euthanasia, "sweet and easy death", which refers to programmed death, practiced by someone, which meets the expressed will of the individual or his family and legal guardians, when he suffers from painful illness and with no prospect of cure (CABRERA, 2010; SILVA et al, 2014). In Brazil, the practice of euthanasia is prohibited, according to the Codes of Medical Ethics (CEM) (CFM, 2018) and the Code of Ethics for Nursing Professionals (Cepe) (CFE, 2007), and the Brazilian Penal Code (DOSSI, 2017), in effect, specifies euthanasia as a crime, and the medical professional who shortens the life of a patient, despite justifying solidarity and compassion, will answer for simple homicide and subject to the penalty of 6 to 20 years of imprisonment, because in this way it would be transgressing the principle of inviolability of the right to life, fully guaranteed by the Federal Constitution (CFM, 2018; CFE, 2007; CABRERA, 2010).

In contrast, in some countries, such as Holland, Belgium, Switzerland and Luxembourg, Uruguay, Colombia, Canada and in five American states: Washington, Oregon, Vermont, New Mexico, Montana and California, where euthanasia is ensured and based on the principle of quality of life, which is justified on the idea that life without a perspective of physical, mental, psychological and social well-being is not worth living (FELIX et al, 2013; SIQUEIRA-BATISTA et al, 2005; PAIVA et al, 2014). However, it is worth noting that active euthanasia practiced intentionally and at the request of a patient is prohibited in all US states. The fact allowed - and which was the subject of controversy submitted to the North American Supreme Court - refers to assisted (medical) suicide. In this sense, the Supreme Court of that country was in favor of the constitutionality of the Oregon law in 2006 (physicianassisted suicide law). The same is true for the other North American states mentioned, which have laws that regulate assisted suicide (FELIX et al, 2013; ALISSON, 2016; SCHADENBERG, 2018; PENALVA, 2008). Passive euthanasia, a concept that is close to that of orthothanasia and accepted by some professional medical societies and the law under certain circumstances, is permitted in the USA. However, it is not permitted for a health professional to actively intervene by ending a patient's life at his request, which the Supreme Court legitimized was that life support was turned off under certain specific circumstances (NANCY

CRUZAN v. State of Missouri, 1990). The term dysthanasia, also derived from the Greek dýsthanasía, means "bad death", is defined as the useless extension of the patient's life without the possibility of improving his clinical condition or cure. It is related to the adoption of superfluous therapeutic procedures that prolong the suffering of terminally ill patients, disregarding their comfort and dignity, as well as the very humanization of the dying process. This practice is based on the use of technological apparatus to maintain physiological life. The justification would be the attempt to "cure" the patient at any cost, as a heroic act on the part of the assistant team. The process is called medical futility, by the Americans and obstinacy or therapeutic incarnation, by the Europeans (GARCIA, 2011; SANTORO, 2010).

A study carried out by Silva et al, in 2014, notes that the majority (64.2%) of the relatives of patients with advanced diseases and with no possibility of cure admitted to a private hospital opted for dysthanasia, thus demonstrating total ignorance of the importance of the institution of palliative care for terminally ill patients, without considering the relevance of dignity in the dying process. This may denote that these families may have been deprived of psychological, social and religious support to support and comfort them in the moment of loss, depositing all their convictions and expectations in the technological apparatus of medicine with the heroic objective of saving the life of their relative. One cannot exclude other feelings regarding family members, such as: the lack of outcome and conformity in relation to the terminal state of the loved one; the religious belief in divine providence, as well as the attachment to the conception that only God can take life and that the person only lives as long as he wants to; the guilt of letting him die without trying to do "everything in reach"; or even the family's financial dependence on the terminal patient (SILVA et al, 2013). Currently, the search is for orthothanasia. Orthothanasia, from the Greek orthos "straight, right" more thanasía, "death", means dignified death; it is the respect for death in its natural rhythm, when faced with the impossibility of cure (PAIVA et al, 2014). The practice defends that the doctor, in the face of imminent death and the ineffectiveness of any therapeutic treatment, proposes to the patient and his family the introduction of palliative care, allowing death to come with less suffering and anguish for the patient, which makes it more dignified and humane (SANTORO, 2010). That is, palliative care is a form of treatment. The practice of orthothanasia is supported by the Federal Council of Medicine (CFM), in accordance with CFM Resolution 1,805 / 2006, which understands it as an appropriate approach to patients who are in the terminal stage of an incurable disease. The resolution authorizes the doctor to limit or suspend procedures or treatments, which postpone the lives of these patients, respecting the will of the person and their legal representative, and can be made available to doctors by authorization from the family (CFM, 2006). In the Brazilian criminal legal system, orthothanasia is considered atypical, since it corresponds to the promotion of lawful activity, since it does not aim to shorten the patient's life, only to formalize an irreversible situation of inevitable death (PAAIVA et al, 2014; GARCIA, 2011). The complexity of orthothanasia and the institution of palliative care requires a weighing and decision process by the terminally ill, their family or legal representative. As this may be the final decision or one of the last of the person, it requires intense reflection that must be assured and supported by the medical team, to provide scientific evidence based on evidence, which gives these people the confidence and security

for decision making, taking into account cultural values and beliefs (RODRIGUES *et al*, 2015). So that, the fundamental objective of palliative care is to promote the comfort of pain and suffering, psychological support, social support and spiritual support, mainly to resolve negative feelings such as: impotence, anxiety, failure, omission, refusal, sadness, pity, frustration, revolt, depression, anguish and emotional exhaustion (CRMSP, 2008) 23, often associated with terminality. This will also help the terminally ill family to deal with the denial of death and awareness of it (RODRIGUES *et al*, 2015).

Palliative care is a set of practices and measures aimed at the end of life of patients without therapeutic possibilities of cure 7. In this context, health professionals must be prepared and turn to the understanding that the priority is the relief of pain, symptoms and suffering of the terminally ill, provide comfort for him and his family, promote dignified and humanized death, encourage the patient to live with his loved ones and minimize the consternation associated with terminality (BARBOSA, 2006; WHO, 2002). The improvement of the medical-technological apparatus was accompanied by the possibility of significantly increasing the survival of patients, including those with incurable diseases. As a result, there is a need for an imminent increase in discussions on terminality and palliative care, which should be encouraged, both within the scope of teaching, covering all courses in the health area of university institutions, as well as medical residencies, health committees in institutional and hospital ethic researchs. Broad debates should be promoted to generate reflection on the topic, in order to allow the adoption of more humane parameters to deal with death. In order to minimize the pain and suffering of terminally ill patients, full knowledge and acceptance of society on the best way to deal with painful, imminent and inevitable death is essential.

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