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Dysthanasia and palliative care: nursing in palliative care

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Abstract

According to the World Federation of Right to Die Societies, the term Comfort Care is often used as Palliative Care. Palliative Care encompasses in its concept the management of pain and symptoms, support for the patient and the family, having the opportunity to achieve a meaningful closure for life. Thus, the article focuses on different texts to understand the role of the nursing professional in maintaining and promoting health with a view to palliative care. The purpose of this article is: in the national scientific scenario, how do palliative care and dysthanasia present themselves in the field of nursing? The bibliographic review as a data collection technique was selected, in line with the expectations of this work, which consists of presenting a broad discussion on the subject in question. Palliative Care does not mean interrupting medical treatment in its entirety, but prohibiting aggressive and invasive treatments, avoiding dysthanasia, that is, it is an opposition "to euthanasia because it consists in the use of all possible therapeutic means, to delay as much as possible the moment of death", in this sense "the increasing use of state-of-the-art technology reflects in the increase of dysthanasia, having as a scenario the commercial-business context, in which the therapeutic procedure continues as long as the patient does not die. This work was carried out from a search on the Google Scholar platform, PubMed, Virtual Health Library (VHL) and Capes Portal. The descriptors used were "Palliative care", "dysthanasia" and "nursing care", applying a time frame from 2015 to 2023, selecting 30 articles with titles associated with the terms "nursing and complications associated with palliative care".And the total of 28 articles that meet the theme. From the analysis of the articles, it was noted that the professional nurse, in palliative care, must be able to make accurate assessments, lead, plan and have a human look when practicing care. These assessments result in the ability to develop plans to deal with symptoms and side effects: constipation from narcotic analgesics, vomiting, lethargy, insomnia, anxiety, and dyspnea. From the analysis of the articles, it was noted that the professional nurse, and the multidisciplinary team in palliative care, must be able to make accurate assessments, by implementing techniques to minimize these problems that are painful for patients and families in the face of the suffering caused by the disease. This study will contribute to the improvement of nursing care in "Palliative Care and knowledge about dysthanasia and demonstrate that several interventions of little technological complexity such as (attention, affection, support, bath) have the ability to significantly affect the comfort status of patients.

Keywords: dysthanasia, palliative care, nursing, virtual health library, world health organization

Abbreviations: VHL, virtual health library; SUS, unified health system; MTSM, mental health workers' movement; IAHPC, international association for hospice & palliative care

Introduction

What factors, if any, contribute to the growing anxiety about death? What happens in an evolving field of medicine in which we wonder whether it will remain a humane and respected profession or a new but depersonalized science whose purpose is to prolong life rather than to mitigate human suffering?

The World Health Organization, in its revision of 2002, updates the concept of Palliative Care - created in 1990 - highlighting that "Palliative Care is an approach that promotes the quality of life of patients and their families facing diseases that threaten the continuity of life, through the prevention and relief of suffering", requiring "the early identification, assessment, and treatment of pain and other problems of a physical, psychosocial, and spiritual nature". Thus, palliative care affirms life and views death as a natural process - of biological order -, without pretensions to advance or delay death: it offers a support system to help patients live as actively as possible until death and family members the support they need from the nursing staff and the entire multidisciplinary team. [1]

The way that Palliative Care is presented today is the product of a complex trajectory that, historically, crosses with the term Hospice.[2] Records point out that the term dates back to Christian times - approximately the 5th century - and goes back to the logic of shelters (inns) aimed at pilgrims and travelers. However, in a pioneering way, Dame Cicely Saunders, in the 1970s, introduced the Modern Hospice Movement, when, in the exercise of her nursing training, she met David Tasma, 40years old, Jewish, and offered a palliative colostomy due to an inoperable rectal carcinoma.[2] Visits and long conversations remained, until the death of David, who, in a will, leaves in writing, next to a small inheritance: I will be a window in your house.

Cecily Saunders committed herself to the new possibilities of health care, in a more humanistic way, and in 1967, institutionalized her commitment, founding St. Christopher's Hospice, whose structure accommodated patients and the development of teaching and research. In this way, today, as we know it, through Cecily Saunders' impulses, Palliative Care does not mean interrupting medical treatment in its entirety, but interdicting aggressive and invasive treatments, avoiding dysthanasia, that is, it is an opposition "to euthanasia by consisting in the use of all possible therapeutic means, in order to delay as much as possible the moment of death", in this sense "the increasing use of state-of-the-art technology reflects in the increase of dysthanasia, having as scenario the commercial-business context, in which the therapeutic procedure continues as long as the patient does not die or as long as there are resources to do so".[3]

According to the World Federation of Right to Die Societies the term Comfort Care is often used as a synonym for Palliative Care. Palliative Care encompasses in its concept the management of pain and symptoms, support for the patient and family, and the opportunity to achieve meaningful closure to life.[4] Thomas Smith, director of palliative medicine and professor of oncology at Johns Hopkins, explains about the importance of family members at the time of hospitalization, "Actually, looking at people who use hospice, spousal survival is higher. It's really fascinating."

Nurses working in palliative care have a constant focus on end-of-life care. Nursing availability is 24 hours/day and is directed at pain, side effects and symptom management, in addition to family support and will have good listening skills,[5] as they do not only focus on pain and other symptoms, but also on compassionate listening, education, guidance and counseling. In this process, nursing professionals enable quality of life for the patient and their family.

From this perspective, studies aimed at the construction of thought about the role of nurses in palliative care are essential. Thus, the article focuses on various texts to understand the role of the nursing professional in the maintenance and promotion of health in view of palliative care. Thus, the guiding question of this article is: in the national scientific scenario, how is palliative care presented in the nursing field? Thus, in order to obtain data, this study was based on a literature review, highlighting texts aligned with the objective.

Methodological Approach

Considering that the objective of this work is to present a dialog between nursing and palliative care, proposing to understand the proximities of the fields, conceptualizations, and limitations so that they can be effective as complements, the bibliographic review, as a data collection technique, was selected, aligning itself with the expectations of this work, which is to present a wide discussion about the theme in question.

In this sense, a bibliographic review was conducted with different types of academic texts (scientific article, Course Conclusion Work and book). According to Cavalcante and Oliveira,[6] this technique "allows a broad description of the subject, but does not exhaust all sources of information, since it is not carried out by systematic search and analysis of data. Its importance lies in the rapid updating of studies on the theme", allowing the historical rescue and the evolution of the theme based on academic texts - and others - published. That is, "the bibliographical research has exploratory nature, because it allows greater familiarity with the problem, improvement of ideas or discovery of intuitions".[7]

This work was conducted from a search on the Google Academic platform, which presented the bases PubMed, Virtual Health Library (VHL) and Portal Capes. The descriptors used were "Palliative Care", "dysthanasia" and "nursing care", applying a time frame from 2015 to 2023, in which 30 articles were located. Thirty articles were selected with titles associated with the terms "nursing and complications associated with palliative care" and 10 articles were discarded due to the duplicity of the sample, for not addressing complications related to GVHD and articles not located in their entirety. After reading the articles, 28 articles were included because they described problems encountered in palliative care practice. 10 articles were excluded for not being in English or Portuguese and for not bringing a approach related to the proposed theme.

Nursing practice and the principles of bioethics

Life went on, but between ups and downs, the natural course of the disease led to the amputation of the legs. The hope that the pain would go away with the amputation also ended quickly: it persisted. Terrifying diagnosis for a child: my grandmother had phantom pain. Phantom pain... Would it have been possible to exorcise it? Send the phantom pain on its evolutionary path? To take it out of purgatory and release it into the heaven of pains? Or could we condemn it to hell, where it would stay for all eternity and never frighten anyone around here again?

The passage from Quintana's book, "death is a day worth living", which begins this section, makes us think about the fundamental principle manifested in the Federal Constitution (1988): there is a guarantee, that is, it covers all aspects of the right to human life, which is to live with dignity from conception to death. That said, in addition to the principle in question being applicable in all dimensions of the social and facing the challenges of the effectiveness of integrality, investigate the principle, especially, in health management and the termination of life with dignity, it is realized that there are still several complexities to be understood and overcome.[4] With regard to the problem of this text, serious and incurable diseases, the Federal Council of Medicine points out, in Resolution No. 1.805 of November 9, 2006, in Article 1, that: Art. 1. Doctors are allowed to limit or suspend procedures and treatments that prolong the patient's life, avoiding Dysthanasia and ensuring the necessary care to alleviate symptoms that lead to suffering, within the scope of integral care, respecting the patient's wish or that of his/her legal representative.

Félix et al. point out that dysthanasia refers to a process, although little known, but too often practiced in health care, that prolongs the life of patients in terminal stages, in a way that does not pay attention to physical and psychological pain, that is, it is "a difficult or painful death, used to indicate the prolongation of the process of death, through treatment that only prolongs the biological life of the patient, without quality of life and without dignity".

There are, however, precarious social mechanisms that make it impossible for the individual to become a patient, thus abandonment and premature death by neglect configure mistanasia. The term is associated, therefore, "with the death of thousands of people without any assistance, left to their fate, in dumps, under bridges, overpasses, streets and, especially, in hospitals with crowded corridors, with dying patients abandoned by the State".[8] It is a process of "nadification" of subjects that occurs in two ways, active and passive: "mistanasia consists in the miserable death, early death of a person, resulting from human malice (active mistanasia) or from medical or institutional malpractice (passive or omissive mistanasia)".[9]

That said, it becomes interesting to infer the idea that mistanasia and orthothanasia are synonyms, that is, that they refer to the same process. Mistanasia is a process that prohibits the final process of life with practices of marginalization of subjects, of disrespect towards individuals who need to become patients, after all "there is no humanitarian treatment whatsoever, nor does it happen by therapeutic obstinacy in eventually luxurious hospitals, as is the case of dysthanasia. It occurs by abandonment, neglect and helplessness".[8] Thus, misthanasia is fully opposed to orthothanasia, which is practiced according to the wishes of the terminally ill patient - and is not configured as an unlawful act. Thus, "orthothanasia is the non-

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artificial prolongation of the death process, it is considered by many as a desirable death, because it does not increase the life span through methods that could bring suffering".[10]

Considering CFM Resolution n. 1,805/2006, in order to ensure the dignity of the human person, it is assured to the patient to receive the necessary care to alleviate the pain that the disease is causing, and this assistance treats from physical pain to psychological pain, both of the patient and his family, and prepares them for the inevitable moment of the end of life: Art. 2. The patient will continue to receive all necessary care to alleviate the symptoms that lead to suffering, assuring integral assistance, physical, psychological, social and spiritual comfort, including assuring the right to hospital discharge.

This resolution was considered a great advance for the implementation of palliative care. On the other hand, on May 9, 2008, the Federal Public Ministry filed a Public Civil Action with the intention of recognizing the nullity of the aforementioned resolution. The Federal Public Ministry was successful with regard to the anticipated injunction, which was granted, immediately suspending the effects of the Resolution in question. Dissatisfied with the decision, the Federal Council of Medicine filed an interlocutory appeal.

After the fervent discussion between the parties, on December 1, 2010, a favorable sentence was handed down to the Federal Council of Medicine, revoking the preliminary injunction that suspended the effects of Resolution nº 1,805/2006: the exercise of Law 7498/86 that regulates the exercise of nursing is enlightening in the sense of establishing the threshold that surrounds the terrain of the nursing profession. It is paramount to punctuate, within the scope of legislation, and in terms of updating practice, that Resolution No. 41, of October 31, 2018, was published, providing on the guidelines for the organization of palliative care, in light of integrated continuous care, within the Unified Health System (SUS), with an organization established from several objectives. The question is: what is the role of the professional nurse in the practice of palliative care?

In terms of Law 7498/86, the issue of humanity that must be present in the daily activities of the nursing professional is emphasized. This complexity in the work of the nursing professional should be in the curriculum, in the internship practice, and especially in dealing with the patient. It stands out here, therefore, even though in the medical field, the insertion of the discipline, Palliative care, which is taught by the writer and medical professor Ana Cláudia, Quintana Arantes,[11] in the state of São Paulo, In which it understands the gaps that constitute the health field and allows itself to act in higher education to overcome, in loco, the precariousness of teaching. That said, Rocha[12] points out that the function of the nurse transcends the labor issue. Thus, the nurse's function is not only assistential, but has a strong component of transformative action in the economic, political, and - also - educational reality in which he or she operates.

According to Rocha,[12] the work of the Nursing professional is performed jointly by a team, among which there are different degrees of training, similar in that society does not differentiate the categories that make up the nursing team, i.e., the existing hierarchy goes unnoticed by people in general. According to Donoso and Donoso,[13] nursing can be defined as the art and science of assisting the patient in their basic needs. And, when it comes to palliative care, one can add that nursing seeks to contribute to a more dignified survival and a peaceful death [14,15,16]. After all, When a patient is seriously ill, he is usually treated as someone who has no right to have a say. It is almost always someone else who decides whether, when and where a patient should be hospitalized. It would cost so little to remember that the patient also has feelings, wishes, opinions, and above all the right to be heard.

The general skills and competencies required of nurses are related to health care, decision-making, communication, leadership, administration and management, and continuing education.[17] Thus, the nurse takes the role of manager of nursing care.[6] In this sense, to address the care of the other, establishing trust on both sides, through listening, the other's speech, in addition to the perception of limitations. From this perspective, the team needs to strengthen relationships with patients and their families. These relationships must be in accordance with the principles of Biomedical Ethics: autonomy, beneficence, justice, maleficence, and precaution. Such fundamentals regulate the professional practice in the health area, but bioethics influences several areas, with the objective of making professionals understand their limits and responsibilities, as well as their rights and duties towards society and their clients. Therefore, bioethics encompasses topics from genetic manipulation to environmental management. Governing, in the clinical area, issues that generate conflict, from the beginning to the end of life.[18]

In this sense, Bioethics is a field in movement, which enables the insertion of diverse and current themes, to identify processes that respect life. Let's see: "in relation to Palliative Care in the process of Death and Dying, Bioethics defends what we call orthothanasia".[18] This term refers to the death process that occurs naturally, without acceleration of death, or its prolongation. It is a natural death, but assisted by the multiprofessional health team, so that it meets all the needs of the client, as well as alleviating and preventing possible aggravations, following then, the principles of Palliative Care.[18]

The bioethical discussion - the human and individualized care - allows the professional nurse to be aligned with the scientific knowledge assimilated, enabling openings for a knowledge to be built throughout the exercise of the profession, which ensures that the nurse is willing to listen to the patient and talk about his treatment. Moreover, the nurse's communication with the patient and their families should occur through a bond of trust, in which the professional identifies the important points of attention and guidance.[19,20]

The nurse and palliative care

Palliative Care nursing" is described in the literature through a study by Seymour,[21] who conducted this analysis of care, assuming this skill as the object of study. This study evidences that such expression first appeared in the United Kingdom, in 1989, by a group of specialists of the Royal College of Nursing, who were interested in discussing the performance of nurses in cancer patient care and the whole history of the origin of palliative care. In this dimension of care, the patient and his family decide about treatment about the disease and the process of hospitalization and should be informed, in advance of the decision, about the quality of communication between nursing staff, especially in the terminal phase, thus creating a safe environment, therefore, with effective actions that best represents palliative care in nursing.[4]

By shifting the horizons from illness to health, health promotion and education programs are conceived, whose nurses' activities are permeated by responsible attention to all the processes involved: planning, execution, and evaluation are essential elements for the promotion of health programs.[22] Thus, in contrast, palliative care, which is intended for individuals in the last months or weeks of life, addresses a variety of physical, psychosocial, emotional, social and spiritual needs of patients and their families.[23] It is understood, taking such aspects into consideration, that the planning and implementation phases of any healthcare program are related to ensuring good outcomes.[24]

When conducting health promotion or health education activity, most nurses do not usually take into account all the constituent elements of a program's process. Regardless of the type of approach or intervention, all health-related programs require an evaluative component. The second evaluation approach is concerned with measuring an activity against a standard that may or may not be related to the specific objectives of the activity (process evaluation/evaluation).

One can think, therefore, of the exercise of nursing in palliative care, especially in the mental health care of professionals working in this area. It is understood that nursing can be defined as the art and science of assisting the sick in their basic needs and, when it comes to palliative care, one can add that it seeks to contribute to a more dignified survival and a peaceful death. In the book "Death is a day worth living", by the author Ana Claudia Quintana Arantes, there is a weaving about the logic of empathy: it is an ability to put oneself in the place of the other, which, even though it is a positive element in the dimension of care, simultaneously provokes aspects of caution. And compassion goes beyond the ability to put oneself in the place of the other, it allows us to understand the suffering of the other without being contaminated by it. Certainly, "there are many reasons to shy away from facing death calmly. One of the most important is that, nowadays, dying is too sad in many ways, above all it is too lonely, too mechanical and inhuman".[25]

Being mentally aligned to the exercise of the profession is paramount to quality care, safe and humanized. On the other hand, the learning, which is built in practice, or introjected by systematic studies on palliative care, of the nursing professional must ensure the interpretation of verbal complaints, body expression, physiological signs. These are processes of preparing, training, to deal with the death cycle - as something natural. It is attested that "it is necessary for Nursing to develop strategies so that this does not affect it so harmful in the long term". And this requires the mandatory assimilation of the fundamentals of bioethics: autonomy, beneficence, maleficence and precaution.[17]

Gastmans and Milisen[26] teach that the ethical basis for a number of concrete recommendations that could provide clinical and ethical support for caregivers when making decisions about physical restraint, for example. Respect for the autonomy and general well-being of older people, a proportionate assessment of advantages and disadvantages as a priority goal the alternatives for physical restraint, individualized care, interdisciplinary decision making, and an institutional policy are the central points that make it possible to deal responsibly in caregiving.

In Brazil, the offer of palliative care is still focused on hospitals and, even so, only 10% of these institutions have a specialized team. Other authors argue that the integration of palliative care in primary health care can solve the absence of specialists in palliative care, becoming a tangible starting point in the transformation of the current reality.[27] This scope enables the expansion of the understanding that therapeutic communities begin to seek the humanization of hospitals.

In the 1970s, "the Brazilian psychiatric reform movement begins to be constituted, with the Mental Health Workers' Movement (MTSM) gaining expression", initially incorporating "criticism to the hospital centrism, the poor working conditions", in addition to the poor treatment conditions and the occurrence of the privatization of psychiatric care, marking its entry into the public apparatus signs of end-of-life: the final days and hours - breathing difficulties (long periods without breathing, followed by rapid breaths), drop in body temperature and blood pressure, less desire for food or drink, changes in sleep patterns, confusion or absence.[28]

Health promotion implies having policies described in the law, which is the case of Brazil in applying them, in what we still owe in terms of practice. Public health nurses play a significant role in improving the health status of communities. The health of the population can be maintained and improved through institutional sector changes and support for health promotion. An integrated care network between emergency, specialized, and primary care services can prevent repeated hospitalizations and institutionalized death of terminally ill patients in palliative care. To identify the perception of health professionals about the concept of palliative care and their experiences of caring for this type of patient in a pre-hospital care service in Brazil.

It is necessary to invest in professional training associated with palliative care in the home setting and its principles, such as: affirm life and consider death as a normal process, not hastening or postponing death; integrate the psychological and spiritual aspects of patient and family care, including grief counseling and improving quality of life, adopt a specific policy for PC that involves all levels of care, including PHC, and adopt a unified information system, in addition to more effective procedures that favor respect for the patient's wishes, without generating dissatisfaction to the team and the family.[27]

The World Health Organization defines palliative care as "care provided by a multidisciplinary team that aims to improve the quality of life of patients and their families in the face of life-threatening illness through prevention and relief of suffering, early identification, impeccable assessment, and treatment of pain and other physical, social, psychological, and spiritual symptoms. In addition, it recommends the beginning of palliative care at the moment of diagnosis of the disease, and not only at the end of life, recommending the integration between services at all levels of care, with a focus on directing primary health care.[27]

The International Association for Hospice & Palliative Care (IAHPC) proposed and developed a project for the adoption of a new definition of PC about what it is, when it should be applied, to whom and by whom, covering all dimensions of life. It suggests offering holistic and active care to all people experiencing intense suffering, arising from diseases with no possibility of cure, especially those at the end of life. It also aims to improve the quality of life of patients, families, and caregivers who face issues associated with life-threatening chronic diseases through the prevention and relief of suffering.[27] In this sense, the guiding principles of PC are:

a) Start palliative care follow-up with disease-modifying treatments as early as possible. Include all necessary research to understand the best treatment and management of the presenting symptoms.

b) Reaffirm life and its importance.

c) Understand death as a natural process without anticipating or postponing it.

d) Promote assessment, reassessment, and impeccable relief of pain and other discomfort-generating symptoms.

e) To perceive the individual in all his/her completeness, including psychosocial and spiritual aspects in his/her care. For this, a multidisciplinary team is essential.

f) To offer the best support to the patient by focusing on improving the quality of life, positively influencing the course of the disease when possible, and helping the patient to live as actively as possible until death.

g) Understanding family members and loved ones as an important part of the process, offering them support and assistance during the patient's illness and also in the grieving process after the patient's death.[29]

The provision of palliative care covers a wide variety of settings, including hospitals, hospices, nursing homes, and homes, and this care is generally classified when performed by general practitioners, who play a key role in an integrated palliative care model, applying their knowledge and skills to care for the patient. Certainly, they also promote patient and family care and/or coordination and information to other specialist health services, hospices and home care, to help them provide support for the patient and family.[27]

Regarding nursing, Franco et al.[18] suggests an attention to the promotion of psychosocial and spiritual support, after all, it is little applied in the exercise of the profession, indicating that this little accessed approach "may be related to its current form, which is abstract for professionals, being difficult to identify, diagnose, prescribe care, execute it and still evaluate its results". It is about, as an evaluator, the professional nurse pointing out the needs that are not being accessed and proposing solutions, so that "psychosocial and spiritual needs do not cease to be one of them, then supports for these should be proposed and executed".[18]

In addition, nursing must be committed to the psychic dimension of the family members, after all, the grieving process, which begins when announcing palliative care, provokes feelings such as anger, frustration, helplessness. This means that respectful, trusting and empathic communication is necessary, which will serve as a bridge to cultivate empathy, compassion, in the multiprofessional team.[30]

Conclusion

When we approach terminal diseases, the terminality of life becomes a very important issue, and what will be the procedure to be taken when the time comes is something to be emphasized in a subtle but effective way, so that the patient and his family are aware of which procedures can or cannot be performed. In this decision making process, the patient and his family members have the right to express their opinion about the processes of a dignified and comfortable death.

The professional nurse in palliative care must be qualified to make accurate assessments, lead, plan, and have a human eye when practicing care. These assessments result in the nurse's ability to develop plans for dealing with symptoms and side effects: constipation from narcotic analgesics, nausea and vomiting, lethargy, insomnia, anxiety, and dyspnea. The nurse and the multidisciplinary team are responsible for implementing techniques to minimize these painful problems that occur with patients and family members who are present in the face of this suffering be it a loved one, family member, or friend. This care serves to make the patient and family more empowered about the processes and, supported, comfortable and less distressed.

It is through the process of death/dying that the nurse with his team is inserted daily in care and always be seeking to improve knowledge to meet all who require such care, and thus bringing dignity, quality and comfort to patients and families. It is important to point out that health promotion implies having policies described in the law, which is the case in Brazil, and applying them, but we are still lacking in terms of practice. Public health nurses play a significant role in improving the health status of communities. The challenge for regional health authorities is to support the shift from care for diseases with no possibility of cure to a focus on Palliative Care.

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