

Palliative Care in the Process of Human Terminality: Integrative Review

REVIEW

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Abstract

Objectives: To characterize the scientific production on Palliative Care in the process of human terminality in the Health field, from 2007 to 2016.

Methods: Integrative review of the literature conducted in September and October 2016, available from the Virtual Health Library through the electronic databases: SciELO, LILACS and BDENF. The guiding question was: What is the characterization of the scientific production on Palliative Care in the process of the human terminality disseminated in online journals in the Health field, from 2007 to 2016? The study sample consisted of 27 publications related to the investigated topic, using the descriptors "palliative care and terminality". The analyzed data were grouped and presented in figures.

Results: From the selected publications, two thematic categories emerged: *Palliative care to the terminal patient with an emphasis on humanization* and *Assistance to the terminal patient in palliative care*.

Conclusion: This review verified that the production is incipient, and that technical and humanized actions guide the practice of palliative care.

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Keywords

Palliative Care; Terminality.

Introduction

In the middle of the 20th century, technological advances, coupled with the development of therapeutics, enabled recognizing many life-threatening pathologies as chronic diseases, promoting the longevity of individuals affected by those diseases. Thus, out-of-ward patients cluster in hospitals, constantly receiving inadequate care, often focused on an attempted recovery, using invasive, high-tech methods. Those behaviors, now rare and, sometimes, excessive and unnecessary, result from the ignorance on an assistance focused on the real needs of the individual with life-threatening diseases. It is noteworthy that those professionals usually ignore the suffering and are unable to treat the most prevalent symptoms, since they do not have the qualification for that type of care, with the pain as the main and most dramatic [1].

Bertachini and Pessini [2] mention that palliative care arose in response to the intense technological perception that has occurred in the last decades. In this line of thought, one verifies, in that care modality, that the patient is seen in a holistic way, considering the biopsychosocial and spiritual aspects. In this step, the family is also valued, and should receive assistance that goes from the moment of the disease diagnosis to mourning.

Thus, Palliative Care is an integrated and multidisciplinary therapeutic modality, intended for patients suffering from life-threatening illness. It seeks, through total and active care, to provide quality of life for sick people and family members, minimizing their physical, psychosocial and spiritual suffering during the termination process [3].

It is noteworthy that, in 2012, the World Health Organization [4] (WHO) stated that palliative care is an approach aimed at improving the quality of life of family members and patients with an incurable disease, through the prevention and relief of suffering and treatment of the physical, psychosocial and spiritual problem. Thus, palliative care focuses on patients suffering from incurable diseases, often

evolving into the process of life termination and requiring humanized care that involves their complexity.

Just like birth, the moment of death is unique and alone. Caregivers and family members describe it succinctly as a time of much suffering, even when the symptoms are well controlled. The precise conceptualization of the beginning of the last hours is not exact in the literature. However, that definition transcends the real need, which is the identification of that time surrounded by exacerbated symptoms, which requires alteration of the treatment plan and continuous care [5].

Despite all efforts, Brazil presents a care policy for terminal patients still incipient and disjointed, whose main challenge is to insert palliative care in its Health System. Recent research has shown that Brazil occupies an average plateau of palliative care, behind Argentina, Chile and Costa Rica [6].

Given the exposed, considering the relevance of palliative care for the practice of humanized care to the terminal patient, this research aimed to characterize the scientific production on Palliative Care in the process of human terminality in the Health field, from 2007 to 2016.

Methods

This is an integrative review of the literature, a research modality that has the scope to gather and synthesize pre-existing knowledge on the proposed theme and follows well-defined criteria on the operational stages of the research [7]. Moreover, six phases guide it: elaboration of the question; establishment of the search strategy in the literature; selection of studies based on inclusion criteria; critical reading, evaluation and categorization of content; analysis and interpretation of results [8].

Data collection took place in October and November 2016. The research was conducted based on the following guiding question: What is the characterization of the scientific production on Palliative

Care in the process of human terminality disseminated in online journals in the Health field, from 2007 to 2016?

In order to select the studies, the research followed the pre-established inclusion criteria: articles fully available in Portuguese and published between 2007 and 2016. The Virtual Health Library (VHL) was consulted through the electronic databases: Scientific Electronic Library Online (SciELO), Latin American and Caribbean Literature in Health Sciences (LILACS) and Nursing Database (BDENF). The descriptors used to search for the productions in the VHL were "palliative care", "terminality", with the help of the Boolean operator AND.

In this sense, after reading the abstracts and conducting a floating reading of the articles, 27 articles were included in the inclusion criteria. After selection, copies of selected articles were obtained and a thorough reading of each study was carried out in order to structure the information related to the development of the review, in order to reach the proposed objective.

Subsequently, the obtained data were grouped and presented in tables, in order to enable a better visualization of the studies inserted in the integrative review.

Results

The study sample consisted of 27 articles distributed in periodicals available in the databases selected for the proposed research, highlighting the Bioethics Journal (Impr.), The Journal of the Nursing School of the University of São Paulo and the Brazilian Jour-

nal of Intensive Care. Those journals are technical-scientific dissemination vehicles to foster a multidisciplinary and pluralistic discussion on bioethics and ethics issues in health, as well as health care and the intensive care unit. The other journals add up to 43% of the articles selected in this study.

Regarding the year of publication of the studies included in this review, 2011 presented the highest number of published scientific articles, obtaining a percentage of 19% (five), followed by the years of 2009 and 2013, with 30% (eight) of the publications about the researched subject.

As for the modalities of the studies, there was an expressive quantitative of manuscripts originating from original researches. The original articles stand out, with a percentage of 44% (12), followed by review studies with 26% (seven) and other studies 30% (eight).

The referenced designs contributed to generate new knowledge on the research topic. Therefore, one verifies that the articles selected for this integrative review are researches developed through different modalities of study, mainly original articles and review, that provide the production of new knowledge, amplifying, above all, knowledge of the literature about palliative care and terminality.

With regard to the focus of publications, two thematic categories emerged: Category I - Palliative care to the terminal patient with an emphasis on humanization; Category II – Assistance to the terminal patient in palliative care, which will be presented below (Table 1, 2).

Table 1. Category I. Palliative care to the terminal patient with an emphasis on humanization.

Journal	Year	Title	Parts of the publications
Revista Brasileira de Enfermagem REBEn	2007	The attitude of nurses face the autonomy of the terminally ill patient	[...] terminal patient care requires the health professional to be responsible for articulating the relationships within that triad, as well as communicating effectively with the family and the patient [...]
Rev Bras Ter Intensiva	2008	End of life and palliative care in intensive care unit	In the ICU, communication is a process involving perception of the environment and of the work climate, including non-verbal communication by the multiprofessional team, even the interaction physician/patient and relatives

Journal	Year	Title	Parts of the publications
Rev Esc Enferm USP	2009	Phenomenological study about the nurse's home care for families of terminally ill patients	[...] For families who experience the terminality of one of their members at home, following the precepts of palliative care enables inferring that the patient's home is the place of choice suitable for care, since their quality of life can be favored by living with relatives and friends in their own environment
Re Rev Bras Ter Intensiva	2009	1st Forum of the Southern Cone End-of-Life Study Group: Proposal for care of patients, bearers of terminal disease staying in the ICU	[...] end-of-life practices must prioritize the patient's best interest, respecting his feelings and wishes of the family members as well as adequate communication among all those involved in the process
Revista Cubana de Enfermeria	2010	Palliative care with terminal patients: a focus on Bioethics	[...] to make health professionals aware that patients suffering from unhealed ills need to take care of themselves and focused on them, in order to provide them with dignity and relief for their suffering in that life phase
Cienc Cuid Saude	2011	End-of-life care: listening to the relatives	[...] the importance of the caregiver being assisted by a qualified team from the beginning of that 'journey', with the planning of orientation, support and help interventions
Rev. bioét (Impr.)	2011	Bioética e humanização na fase final da vida: visão de médicos (Bioethics and humanization in the final phase of life: doctors' vision)	In addition to the dignified, supportive and welcoming treatment by health professionals [...], humanization presupposes a new ethical posture that permeates all professional activities [...]
Rev. Bras. Ter. Intensiva	2011	II Forum of the End of Life Study Group of the Southern Cone of America": palliative care definitions, recommendations and integrated actions for intensive care and pediatric intensive care units	The ability and the education and training of the ICU palliative care professionals to reduce the length of stay and improve the quality of provided care are not doubted
Rev. bioét (Impr.)	2012	Meanings of termination of life and palliative care for physicians	[...] physicians [...] always [value] quality of life, not the increased life time, in a limited or incapacitating condition. Upon the natural death, allowing the patient a dignified death, without prolonging life with suffering
Rev. bioét (Impr.)	2013	Nursing professors and the terminality in conditions of dignity	The way each patient lives his/her terminality has to do with the circumstances in which he/she is being cared for, in the dynamics of the ethics of the relationships that are created between him/her and the professionals who assist him/her
Rev enferm UFPE on line.	2013	Bioethics, palliative care and terminality: an integrative review of the literature	[...] a humanized assistance [...] aims to prevent and relieve suffering by controlling the symptoms and involves a multidisciplinary, multidimensional and human care
Ciência & Saúde Coletiva	2013	The significance of death for doctors faced with end-of-life care of patients undergoing bone marrow transplants	[...] making the right decision and following the professional path that makes him/her feel happy to perform certain tasks, which are easy to do, no matter how arduous they may be
Rev. bioét (Impr.)	2014	Ethics in palliative care: conceptions about the end of life	In the perspective of the professional-patient-family relationship, the focus of care should not be directed only to the terminally ill person, but to the entire family group [...]

Journal	Year	Title	Parts of the publications
Rev Esc Enferm USP	2014	The existence of nursing in caring for terminally ill's life: a phenomenological study	Nurse practitioners feel gratification, joy and satisfaction when performing palliative care, [...] overcoming patient-nurse barrier, perpetuating the contact between humans
Revista Baiana de Enfermagem	2014	Palliative care for terminally ill patients	[...] the importance of palliative care is undeniable, in order to enhance the value of human beings in the health-disease process, in order to improve their quality of life, when there is no more therapeutic possibility, and to promote support to their families during the disease and in the process of death and dying
Rev Rene.	2015	Care to the person in a terminal process in the perception of the nursing students	[...] the professional must feel both fulfilled by giving care as restoring the life to the person, just as he/she must also feel his/her duty fulfilled in providing a dignified death [...]
Cuid Arte Enfermagem	2015	Palliative care, diagnosis and terminality: indication and beginning of the process of palliation	Health professionals, mainly from the area of Palliative Care, need to be sensitive to the needs of the population and patients, attending the patient with a more humanized care, with a look at the individual and not just the disease [...]
Rev Esc Enferm USP	2016	The illness experience: Palliative care given the impossibility of healing	It is then "to offer an integrated care, a private attention and enriched by the discussion that transcends the knowledge of each professional"

Source: Research data, 2016.

Table 2. Category II. Assistance to the terminal patient in palliative care.

Journal	Year	Title	Parts of the publications
Rev Soc Bra Clin Med	2008	Palliative care: are there benefits on end-stage-disease-patient nutrition?	Oral nutrition is still the ideal management in patients who are in palliative care
Revista Kairós	2009	Religiosidade e atitude diante da morte em idosos sob cuidados paliativos (Religiosity and attitude towards death in elderly people undergoing palliative care)	[...] religiosity has proved useful for being a source of resources, and facilitating the handling of problems, and can offer relief for negative emotional experiences that compromise the well-being of individuals in those conditions
O Mundo da Saúde São Paulo	2009	Caring for sick people in advanced phases of a disease	When thinking about care for a person with a disease at advanced phase, we must consider that we need to prioritize his/her needs. Those needs, most of the time, are not only in the physical aspect related to the disease, but also in the affective, emotional, psychological and spiritual aspects involved
Psicologia em Estudo	2010	Psychological support in terminality: a lesson for life	The objective of palliative care is to offer the patient and his/her family the best quality of life possible in the time before death
Rev Esc Enferm USP	2011	Music in human terminality: the family members' conceptions	[...] using music as a strategy for nursing care [...] can be used as a tool to bring comfort, reduce pain, facilitate communication and the client-health professional relationship, making care more humanized [...]

Journal	Year	Title	Parts of the publications
remE – Rev. Min. Enferm.	2011	Family caregivers and end-of-life: tendencies of the scientific production in the health field	[...] the presence of the health team is relevant as a support in the process of death and dying of the terminally ill patient, since that situation encompasses both the physical as psychological dimensions
Rev Bras Anesthesiol	2012	Sedação Paliativa do Paciente Terminal (Terminal Patient Palliative Sedation)	In palliative sedation, the objective is to alleviate suffering by using sedative drugs titrated only for symptom control
Ciência & Saúde Coletiva	2013	The task of caring for terminally ill cancer patients	[...] helping the family, helping the patient to have less symptoms in relation to the process is very interesting and fascinating [...]
Esc Anna Nery	2015	Comfort for a good death: perspective of a nursing staff of intensive care	The philosophy of palliative care is an approach that seeks to improve the quality of life of ill people and their families, facing the disease that is threatening the continuity of life through the prevention and relief of suffering. It demands early identification, assessment and treatment of pain and other physical, psychosocial and spiritual problems

Source: Research data, 2016.

Discussion

Category I. Patient palliative care in terminality with emphasis on humanization

In category I, called "palliative care to the terminal patient with an emphasis on humanization", the studies on palliative care provided by professionals from different areas were categorized into patients experiencing the termination process, emphasizing humanization through effective communication, and respect for ethical principles and human dignity, according to **Table 1**.

The experience of caring for the finitude of life in its entirety involves a complex process with great challenges, especially when it involves a chronic, progressive and fatal disease. Mysteries, anxieties, anxieties and fears surround death, raising questions for those involved in that context, that is, the health team, the patient and the family [9].

When an individual is in situations of fragility due to illness, especially the patient outside therapeutic possibilities of cure, strategies should generally associate with a care that promotes comfort and well-being. In that perspective, palliative care is a therapeutic proposal that seeks to analyze the

various symptoms responsible for physical, psychic, spiritual and social suffering, responsible for decreasing the patient's quality of life. Moreover, it is a mode of assistance that aims to see the human being in a holistic way, trying to alleviate pain and suffering, and providing relatives with emotional support [10].

In the practice of palliative care, it is essential to base the care on the well-being of the person in finitude, providing a better quality of life, in order to minimize suffering during the termination process, requiring the team to look closely and cautiously [11]. From that perspective, professionals should develop actions that minimize the impact caused by the disease and are able to provide a quality death [12].

It is necessary to highlight the importance of palliative care directed to the patient in the terminality of life, since it offers a distinct approach to treatment and has, as its main objective, the promotion of humanized care. Care focuses on alleviating biopsychosocial and spiritual needs, significantly aggregating values and cultural practices of the patient and his/her family [10]. Palliative care should take into account all dimensions of the patient without therapeutic possibilities of healing, in

a holistic manner, prioritizing psychological, social and spiritual care, aiming to promote global well-being [13].

Through palliative care, it is possible to construct care directed towards humanized measures, terminally ill patients and without therapeutic possibilities of cure, both at the onset of the disease as in its final phase [14]. This study could evidence the conception of humanized care, revealing that the care promoted by nurses and doctors in their work environment alleviated suffering, providing well-being and comfort [15].

In order to provide care with quality and satisfaction of both the health team as hospitalized patients, the professionals need to be prepared to deal with several situations that require both their autonomy as respect for the diversity of each patient, since they are responsible for decisions involving his/her treatment. It is important to point out that those professionals are qualified to face contexts involving death, since, even though they know it is a natural process, many are still not prepared to experience that work practice. The professionals' qualification is of paramount importance to provide a human, palliative and quality care, and should be carried out periodically to rethink practices, innovate knowledge, in order to improve care [13].

The termination process of an individual's life mainly contemplates those facing a life-threatening illness, which implies coping with numerous problems or symptoms that are representative of large physical or emotional impacts for him/herself, his/her family and the health team responsible for his/her care [3].

Regarding the meaning of terminality of life and palliative care for physicians, one highlighted the terminality of life as indisputable fact and humans differentiate themselves from other beings by the awareness of the finitude of existence. In that context, palliative care has, again, brought the possibility

of humanizing death with respect to the individual's dignity [16].

Thus, professional training in palliative medicine aims to develop teamwork, ability to communicate and qualification given a disease in the terminal phase. Furthermore, those professionals will experience situations of coping with death and mourning with patients, family members and professionals and will need to have support techniques at those times. Hence, it is indispensable to have clinical experience for those patients in the process of life termination [17].

In this sense, the care to terminal patients gives a humanized attention, with emphasis on the palliation, bringing a broader view before the death process in terms of improving the quality of life, even if the cure is no longer possible [18]. Therefore, the process of humanization in health is more than a humanitarian act, since it requires implementing an interdisciplinary and reflective system on the principles and values that govern the practice of different health professionals in the search for their ethical dimension.

With regard to palliative care in the practice of nursing professionals, a study conducted by Mesquita [19] showed that providing humanized care focuses on the patient and family. The understanding of nursing is that palliative care is an indispensable tool to promote care.

Thus, the related studies highlight the performance of professionals working in palliative care, guiding the skills of each professional in the multidisciplinary team. They also point out the evidence regarding the understanding by professionals on the principles that guide the practice of palliative care, through humanized assistance and respect for human dignity [19].

Category II. Assistance to the terminal patient in palliative care

The articles included in category II refer to studies that converge to a care that seeks to improve the

quality of life of patients who experienced the termination process, through therapeutic strategies involving the patient and his/her relatives.

Palliative care (PC) consists of active and total care, aimed at patients with life-threatening diseases, with the objective of improving the quality of life of those individuals, as well as their families, through the relief of pain and biopsychosocial and spiritual problems [4]. In this way, professionals need to develop that care in order to promote comfort, humanization and quality of life, respecting the patient's needs and what he/she thinks is the best, in order to listen to the family members when communication is no longer possible with the patient to the detriment of the advancement of the condition.

The applicability of the PC seeks to minimize suffering in all its dimensions, to alleviate pain and discomfort and, above all, to help relatives accept the death/dying process as something natural in human existence. Thus, it is necessary to offer support and help to the family at the time of coping with the disease and in the process of mourning [20].

The role of the team in terminality involves from the patient to the family/caregiver, promoting relief from suffering, but mainly providing affection and qualified listening in that unique process, allowing the expression of their feelings, longings and desires. Thus, it is essential to control predominant symptoms in that phase, with the team work meeting the needs of the patient and his/her family, strengthening the participation of everyone in the decision making process throughout the process [21].

Palliative care can be developed in an outpatient setting, at the hospital and at home. At the household level, a high degree of humanization permeates the provided palliative care, as it involves the family both in the care as in the affective support of the patient, reducing complications resulting from long hospitalizations [22].

Hospitalization is still the most prevalent choice in the process of illness and terminality, being fun-

damental the presence of a multiprofessional support team that provides attention, affection, zeal, comfort throughout the process, facilitating care based on all physical and emotional aspects [23].

In that terminality process, the medical practice of palliative sedation is considered routine conduct in order to relieve the patient's pain. However, for a dignified intervention, that decision must be shared, there must be consensus among patients, staff and family, as well as psychological and spiritual support should be directed to all those involved in the finite life process [24].

It is worth emphasizing that care in Palliative Care should not be restricted to conventional clinical treatment, since disease involvement and hospitalization tend to enhance emotional fragility and fear, feelings inherent in the terminality process. Thus, it is important to search for psychological alternatives for the patient's balance, such as religiosity, promoting motivation and reinforcing support and help. Fundamental in the scenario of health practices, religiosity motivates the hope of healing, and the respect for the faith, values and beliefs of each being shall prevail [25].

Palliative therapy consists of a set of measures that ensure the patient's comfort and can be performed simultaneously with the interventional and "curative" activities of the Intensive Care Unit (ICU). It is a resource that assists decisions and directs the attention of the health team to ensure the patient's comfort and the family's satisfaction [26].

When palliative care is developed in the ICU, communication is considered a primordial instrument, since the way communication is established can contribute to the approximation or distance between those involved, as family, patient and professionals, which implies directly in the quality of care [27].

It is necessary to clarify that PC seek to preserve the patient's dignity and provide comfort and well-being, which can be achieved through small and simple actions, such as basic hygiene, adequate

attention, comfortable furniture and food. Regarding nutrition, nutritional support in palliative care should minimize the discomfort caused by nutritional therapy of choice, since food is an important cultural habit that integrates care practices [29].

In the same way, musical intervention as a complementary resource in the palliative approach allows assisting in the coping strategies of situations experienced in the process of illness, such as depression, fear and isolation. As a communication resource, that practice should respect the human being as unique and complex, emphasizing an integral and humanized care, in such a way that the use of music provides receptiveness, emotional and affective acceptance, increased self-esteem, comfort and well-being. In that way, the space filled with feelings of anguish becomes a moment of joy and emotion, representing a support of psychological and spiritual support [30].

In that context, the addressed therapeutic strategies emphasize complex care, with the active participation of the patient and family in the process of illness and hospitalization, contemplating various therapies in the management of palliative care, from clinical and pharmacological interventions to complementary therapies. Thus, the integration of the practices leads to a humanized, holistic care, with emphasis on the quality of life throughout the terminality. In that opportunity, through palliative care, one must consider the issue of dignity in farewell to life, providing patients, family members and health professionals with respect for the human dimension of relationships.

Conclusion

This study enabled characterizing the scientific production on palliative care in the terminality process in the Health field, from 2007 to 2016. It verified that the approach of the theme in national journals is incipient. Twenty-seven publications that met the inclusion criteria were identified. There was predo-

minance of studies performed by medical and nursing professionals, revealing that the subject is still little studied in the multidisciplinary context.

From the analysis of the articles, the grouping of two thematic categories emerged: palliative care to the terminal patient with an emphasis on humanization and assistance to the terminal patient in palliative care.

With regard to palliative care of the terminal patient with emphasis on humanization, the studies evidenced that palliative care bases on the patient's biopsychosocial and spiritual well-being, thus becoming a humanized care.

Regarding patient care in terminality in palliative care, this study verified that it is an approach in which technical and humanized actions guide care, aiming at promoting the quality of life of the patient and his/her family during the process of terminality and mourning.

The results of the study draw attention to the need to broaden the discussion on teamwork and the production of knowledge on the exposed theme, in order to contribute to the improvement of the skills and competences of the professionals who work in that area and expand the number of publications at the national level.

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