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INTEGRATIVE REVIEW ARTICLE

FAMILY CARE STRATEGIES IN RELATION TO LIFE TERMINATION
ESTRATÉGIAS DE CUIDADO FAMILIAR FRENTE À TERMINALIDADE DA VIDA
ESTRATEGIAS DE CUIDADO FAMILIAR EN LA ETAPA FINAL DE LA VIDA

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ABSTRACT

Objective: to identify the main strategies of caring for family members who experienced the process of terminality the life of loved ones, as well as whether the care exercised in this process contemplated or not palliative care and covered the physical, social, emotional and spiritual aspects. ***Method:*** integrative review, performed in SCIELO, BDENF and LILACS, between 2011 and 2015, with the descriptors "palliative care" and "family", making a categorization analysis of the 17 articles used for the review. ***Results:*** two types of family coping were identified. The first is represented by family support, spiritual beliefs and care at home. The second, for the support of professionals, and provision of pertinent information to care. ***Conclusion:*** the strategies identified do not require advanced technologies to be implemented. However, an imbrication in the intra-familial, professional and health management spheres is necessary. ***Descriptors***: Home care; Palliative Care; Palliative Care Nursing in the Termination of Life; Family; Health Technologies; Coping Strategies.

RESUMO

Objetivo: identificar as principais estratégias de cuidado por familiares que vivenciaram o processo de terminalidade da vida de entes queridos, bem como se os cuidados exercidos nesse processo contemplaram ou não os cuidados paliativos e se abarcaram os aspectos físico, social, emocional e espiritual. ***Método***: revisão integrativa, realizada na SCIELO, BDENF e LILACS, no intervalo de 2011 a 2015, com os descritores “cuidados paliativos” e “família”, fazendo uma análise em categorização dos 17 artigos utilizados para a revisão. ***Resultados***: foram identificadas duas modalidades de enfrentamento familiar. A primeira é representada pelo apoio familiar, crenças espirituais e cuidado no domicílio. A segunda, pelo apoio dos profissionais e prestação de informações pertinentes ao cuidado. ***Conclusão***: as estratégias identificadas não requerem tecnologias avançadas para ser implementadas. Entretanto, é necessária uma imbricação nas esferas intrafamiliares, profissionais e de gestão em saúde. ***Descritores***: Assistência Domiciliar; Cuidados paliativos; Enfermagem de Cuidados Paliativos na Terminalidade da Vida; Família; Tecnologias em Saúde; Estratégias de Enfrentamento.

RESUMEN

Objetivo: identificar las principales estrategias de cuidado por familiares que vivenciaron el proceso de terminalidad de la vida de seres queridos, así como si los cuidados ejercidos en ese proceso contemplaron o no los cuidados paliativos y se abarcar los aspectos físico, social, emocional y espiritual. ***Método:*** revisión integrativa, que se realizó en SCIELO, BDENF y LILACS, en el intervalo de 2011 a 2015, con los descriptores "cuidados paliativos" y "familia", haciendo un análisis en categorización de los 17 artículos utilizados para la revisión. ***Resultados:*** se identificaron dos modalidades de enfrentamiento familiar. La primera es representada por el apoyo familiar, creencias espirituales y cuidado en el domicilio. La segunda, por el apoyo de los profesionales y la información pertinente al cuidado. ***Conclusión:*** las estrategias identificadas no requieren tecnologías avanzadas para ser implementadas. Sin embargo, es necesaria una imbricación en las esferas intrafamiliares, profesionales y de gestión en salud. ***Descriptores***: Asistencia Domiciliaria; Cuidados Paliativos; Enfermería de Cuidados Paliativos en la Terminal de la Vida; Familia; Tecnologías de la Salud Estrategias de Enfrentamento.

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INTRODUCTION

The process of the terminality of life is a theme still surrounded by many myths and taboos mainly because it brings, in its scope, finitude and death. It seems that "dying" in today's society is not an inherent fact of life but an extremely traumatic event and therefore "must be avoided at all costs." [1-2]

In this scenario of "avoiding death at all costs", discussions about palliative care (PCs) are beginning to emerge, which offer dignity and humanity in the treatment of the person who is in terminal illness. However, they are not restricted only to the patient, because they consider the family essential in this process. It is known that every family nucleus goes through intense suffering since, often, it is up to them to decide the procedures of the treatment.[3]

In order to meet this philosophy of care for individuals with terminal illnesses and their families, the need for a multidisciplinary approach is aimed at improving the quality of life of the terminally ill person and also of their family members when carrying out the prevention and the relief of suffering from a life-threatening disease.[4]

People affected by oncological and cardiovascular diseases and the various chronic-degenerative processes are the ones that most need this model of health care, since they evolve into a framework in which the possibility of cure is minimal or impossible to achieve.[5]

It should be noted that, even with advances in current medicine, there is an increase in the prevalence of chronic diseases, especially neoplasias, associated with progressive aging of the population and lifestyle. Although quality and life expectancy in the treatment of these diseases increased, in 2012, the overall number of deaths due to malignant neoplasms reached 8.2 million.[6]

For this reason, it is salutary to learn to deal with a possible loss in the face of unfavorable prognosis, which is a challenge to the health team and family members. It is known that each family has its own belief system and, consequently, different ways of mourning. Not infrequently, when a terminal illness is discovered, the family, hitherto seen as an organized system, "falls ill" together with their loved one, with a maladaptation in the family nucleus.[7]

Due to the complexity of this care, the family undergoes a restructuring of moral, social, cultural values and behavior adjustment in order to offer the sick family member the best care within their possibilities, knowledge and willingness to cope. It is important to consider that assisting a sick person involves much more than the comfort and hygiene of the same. In this process, feelings of impotence, sadness and stress that need to be worked/re-signified may arise, inherently in the patient and their families.[8]

This study is justified by the researcher's need to understand the complexity of this care process, in the termination of life, faced by family members and health professionals, especially Nursing, serving as a basis for study and guidance for the provision of care these patients and their respective relatives. In view of the above, this study proposed to investigate what the literature refers to the assistance to the terminal patient exercised by family members assisted or not by multi-professional team.

In considering this approach, the following research questions were defined: Which strategy (s) of care and coping were (were) / are (are) adopted by family members who accompany or follow the termination process of their loved ones? Care in the termination process included CPs and physical, social, spiritual and emotional aspects?

OBJECTIVE

- Identify the main strategies of caring for family members who experienced the process of termination of the lives of loved ones, as well as whether the care exercised in this process contemplated palliative care and whether they covered the physical, social, emotional and spiritual aspects.

METHOD

It is a bibliographical research that used the integrative review. In order to elaborate a remarkable integrative review, it is necessary that the steps to be followed are clearly characterized. Thus, the first stage of the process of preparing the integrative review began with the definition of the problem and the formulation of research questions.[9]

In the second stage, the inclusion and exclusion criteria were defined. For this study, the inclusion criteria were complete national and international articles, available electronically free of charge in the Scientific Electronic Library Online (SCIELO) portal and in the databases BDENF (Nursing Database) and LILACS (Latin American Literature and the Caribbean in Health Sciences), which answered the guiding questions and the objectives of the research, published in the interval of 2011 to 2015. For the selection of the exact descriptors, a previous search was carried out in the bases mentioned above. With the descriptor "palliative care", one of the bases resulted in few publications specific to the research theme. One more descriptor was added, that is, "family", to thus fully contemplate the objectives of the study. Summaries published in annals, editorials, book chapters, theses and dissertations, and incomplete articles were excluded. Repeated studies in more than one database were computed only once. The collection was carried out from 03/16 to 03/20 2016.

The third step included the identification of pre-selected and selected studies. The exact descriptors: "palliative care" and "family" were used in all three databases. Then, the following filters were applied: to be an article, with full text and year of publication from 2011 to 2015. From this search, 45 articles were found in SCIELO, 164 in LILACS and 37 in BDENF. A careful reading of the titles, abstracts and descriptors of all the complete publications located by the search strategy was carried out, subsequently verifying if they corresponded to the inclusion criteria of the study and if they fit the theme. In some cases where the title, abstract and descriptors were not sufficient to define their selection, the search for the article was carried out in its entirety. From this analysis, eight articles from the SCIELO database were selected, six articles from LILACS and three from BDENF, according to the scheme of figure 1. Five articles were found in more than one database: two in the BDENF and three in the LILACS. The remaining articles were excluded, as they dealt with ethical issues in palliative care, use of specific drugs or devices in cancer patients, palliative care for patients with degenerative diseases, and difficulties in the implementation and implementation of palliative care.

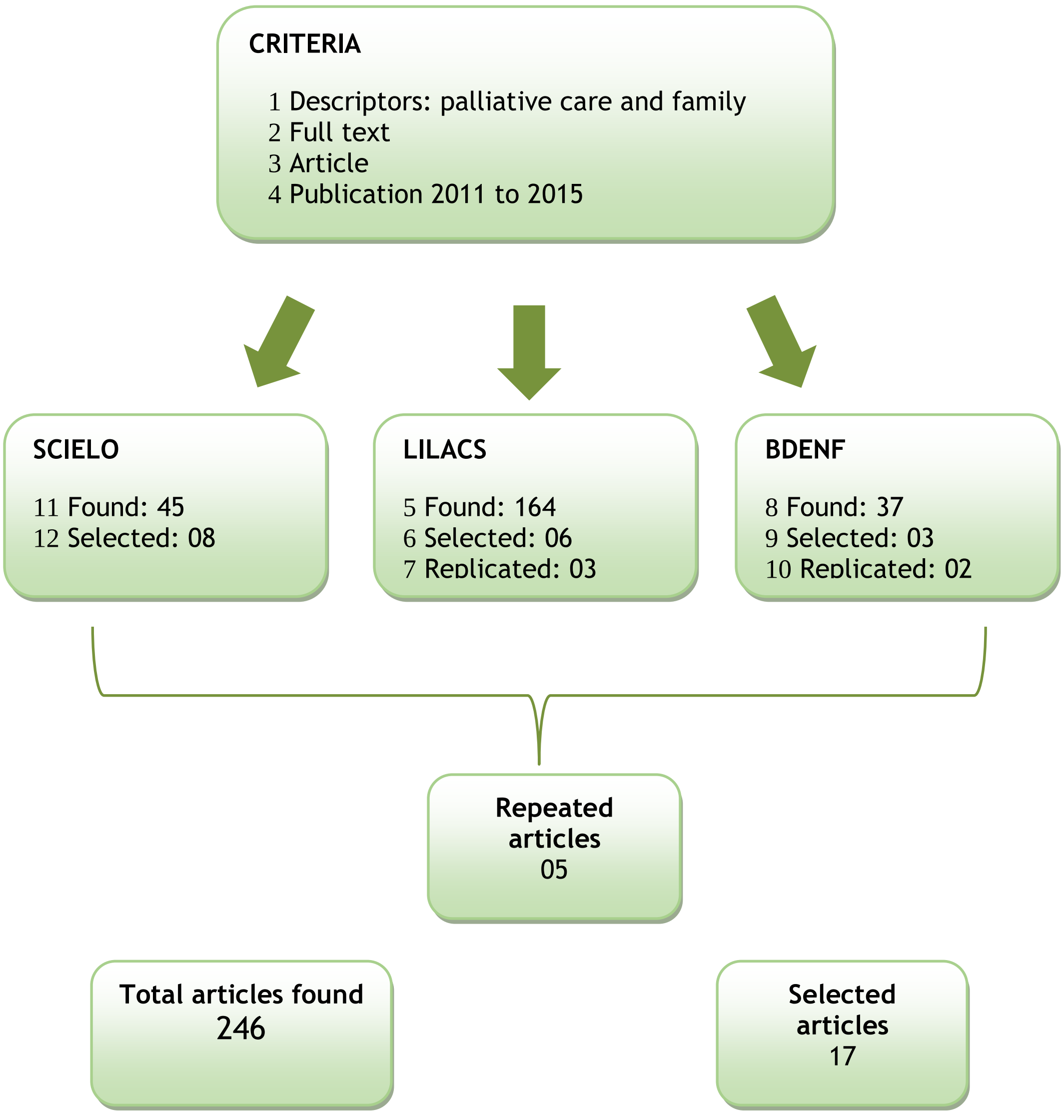

Figure 1. Representative search and selection scheme of articles. Rio Grande, RS, Brazil, 2016.

In the fourth stage, the studies were categorized. For this work, the data extraction instrument was used, which contained: article number, title, publication area, location, objectives, sample, methodology, results, palliative care, aspects contemplated, care strategies used and level of evidence.

The level of evidence is important to know the different types of knowledge production present in the selected articles. These are: Level I - Evidence from Systematic Reviews or Meta-Analysis of Controlled Randomized Studies (RCTs) or evidence from Guidelines for clinical practice based on systematic reviews of RCTs; Level II - Evidence obtained by means of at least RCT; Level III - Evidence obtained through a controlled study without randomization; Level IV - Evidence obtained through case-control or cohort studies; Level V - Evidence obtained through systematic reviews of qualitative and descriptive studies; Level VI - Evidence obtained through a single descriptive or qualitative study; Level VII - Evidence obtained through the opinion of authors and / or expert panel reports. Considering that this classification is based on the type of study design and its ability to affirm cause and effect, levels I and II are considered strong evidence, III and IV, moderate and V to VII, weak.[10]

The fifth step refers to the discussion about the texts analyzed in the integrative review. At this stage, we tried to verify the methods and resources developed and faced by the family group as a way to go through the termination process.

The final step is to present the results. Due to the fact that the review comprises several methodologies, it is necessary firstly to summarize the articles and later segment the information (list below) facilitating the data analysis process and, finally, the presentation of the main results obtained.[9] Another important aspect is that, since this is an integrative review of the literature, it was not necessary to approve the Research Ethics Committee.

RESULTS

Nº	Year	Database and virtual library	Title	Area of pub. /nac.	Identified strategies	Level of evidence
01	22015	SCIELO	Palliative care: challenges for caregivers and health professionals.	Psychology Brazil	The love, affection and affection offered by the relatives were the most activated support resources. Less emphasis on the curative aspect and greater emphasis on the caring process	VI
02	2015	SCIELO	Being cared for by a family member: the existential feelings of cancer patients.	Nursing Brazil	Link between patient and caregiver transcends the difficulties imposed by cancer.	VI
03	2014	SCIELO	Factors influencing end-stage and grief experience: perspective of the primary caregiver.	Nursing Portugal	Allow the end of life to happen at home. Act of caring inherent to the family.	VI
04	2014	SCIELO	Patient well-being followed in palliative care (CP): comparison between patient and family perspective.	Psychology Portugal	Spiritual belief and a good relationship with the family (affection, affection).	III
05	2011	SCIELO	Music in human terminality: the family members' conceptions.	Nursing Brazil	Music as a way to re-signify life, the environment of the patient and improvement in the interpersonal relationship.	VI
06	2011	SCIELO	The family as a therapeutic agent in palliative care.	Nursing Cuba	The qualification of the familiar caregiver in order to qualify care.	III
07	2014	SCIELO	Children and adolescents with cancer in palliative care: family experience.	Nursing Brazil	Faith and religious and spiritual belief.	VI
08	2015	SCIELO	The family's experience of the child and / or teenager in palliative care: fluctuating between hope and hopelessness in a world changed by losses.	Nursing Brazil	Maintenance and carrying out of daily activities. Staying at home as much as possible.	VI
09	2014	LILACS	Nursing in home palliative care: the look of the patient's family member with cancer.	Nursing Brazil	Formal social network[1] and informal[1] family support.	VI
10	2012	LILACS	Experience of professionals and families of patients in palliative care.	Psychology Brazil	Encounter, in religious beliefs, means of how to face and understand the terminality of life.	VI
11	2012	LILACS	Confrontation of the cancer patient and the family /	Nursing Brazil	Spiritual Beliefs.	III

			caregiver before the end of life.			
12	2012	LILACS	Palliative treatment: family perspective.	Nursing Brazil	Reciprocity of care in family / caregiver relationship as a means of coping with difficulties.	VI
13	2011	LILACS	Educational strategy for caregivers of families with terminal illness.	Nursing Cuba	Providing information by a qualified team makes the family caregiver safer and more confident to develop their role.	III
14	2011	LILACS	Family caregiver of the elderly in palliative care: the process of dying at home.	Nursing Brazil	Support of the formal and informal network. Daily life of care and self-knowledge.	VI
15	2011	BDENF	Caring in the terminality of life: listening to family members.	Nursing Brazil	Family support based on previous significant experiences.	VI
16	2012	BDENF	Experiences before death: social representations of relatives of patients out of therapeutic possibilities.	Nursing Brazil	Support in spiritual beliefs.	VI
17	2011	BDENF	Nursing care needs of the person's caregiver under palliative care.	Nursing Portugal	Information about care that facilitates and qualifies care in the termination of life.	V

Figure 1. Main information of articles selected for the study. Rio Grande, RS, Brazil, 2016.

Most articles were published in 2011 (six), followed by 2012 and 2014 (four in each) and 2015 (three).

As for the country of origin of the publications, 71% are national productions and 29%, international. Of the international ones, three articles are from Portugal and two from Cuba. Of the national publications, 41% of them are from the Southeast region, with the South region ranking second, with 33% of national publications.

Regarding the place of development of the studies analyzed, general hospitals predominate (53% of the studies), home care comes second, and finally, specific palliative care units that have a multi-professional workforce. Of the international studies, 100% of them were developed in specific PC units.

Regarding the area of publication of all articles, Nursing leads the number of publications with 82% of the productions. This leadership also refers to national and international publications.

As to the type of study, two were cross-sectional studies; two, studies with educational intervention, but without control; one was a systematic review of qualitative studies and twelve were qualitative studies. Regarding the level of evidence, four presented level III, being sources of moderate evidence; one, level V and twelve, level VI, presenting as sources of weak evidence.

Of the articles analyzed, more than 80% of them were carried out / developed with adults; 12% with children / adolescent and only 6% with people over 60 years.

The profile of family caregivers is predominantly female, ranging in age from 27 to 87 years. The primary caregiver is the spouse, followed by the children, siblings, and grandchildren. In one study alone, one relative hired a non-family caregiver to provide care.

It was found that, in 69% of the studies analyzed, PC was given to patients with malignant neoplasias. In only 21%, PC included both cancer patients and patients with chronic diseases. In 10% (four articles), it was not possible to identify what led to the PC.

Family members used two types of family care strategies in the termination process: one with less emphasis on palliative care, where care was taken at home without the support of a specialized PC team, characterized by feelings of love, affection and caring in the family-caregiver / patient relationship. Also significant is the support received from family members, neighbors and friends who have passed through or experience similar situations of termination of their loved ones. And another with a greater emphasis on palliative care, in which the family has the support of a team specialized in palliative care at both the hospital and home levels.

In the strategy with less emphasis on PC, care was predominant in the home and occurred in two ways: the first, in the situation in which palliative care is not offered by a specialized multi-professional health team, the family and the patient seek the hospital environment in which they do not find conditions of comfort and privacy and, thus, the home becomes the most welcoming place for the last days of life. In the second, when the family has a higher level of education and also a greater contribution of financial resources in which, even the health institution does not offer specific support to PC, the family seeks to be trained for care.

It was noticed that, in order for the family caregivers to develop effective strategies for the care and coping of the end-of-life process of their loved ones, it is necessary to articulate the PCs with the termination process. The care provided in the termination process within the family should be able to meet and meet the needs / difficulties of both involved. While, in the first, relatives need to seek support on their initiative, in the second, there is a favorable context for the reception of these families and terminal patients.

Among the aspects contemplated in the PCs, only seven articles covered biopsychosocial issues. The others contemplated only one aspect or the other. Individually, pain control stands out in the physical aspect and spirituality is one of the least contemplated issues.

DISCUSSION

In relation to the publications of the last years, it was possible to observe a greater number of scientific productions that discuss totally or partially the PCs. Although the greatest number of productions in this study refer to the year 2011, there is a growing need for health professionals to understand the relationships, feelings, difficulties and facilities that families and the health team face in the termination process.

Another important aspect relates to the nationality of the articles surveyed: 71% of the publications are national. Of these, 41% are concentrated in the Southeast, where there are large CP centers such as the National Cancer Institute (RJ), AC Camargo Hospital (SP), Barretos Cancer Hospital (SP), among others. of appropriate teams and structures for this practice of care. In the Southern region (with emphasis on the State of Paraná), 33% of the publications are included, which are part of the follow-up of people in PC at primary care level at home.

A study12 points out three home hospitalization programs within the palliative viewpoint in Brazil: the PID (Household Internment Program of the UH home, of the University Hospital of Clemente de Faria, University of Montes Claros), inserted since 2005.. Also the HHS (Home Hospitalization System) in a hospital in the Rio Pardo Valley, central region of Rio Grande do Sul, and the PIDI (Interdisciplinary Home Hospitalization Program), with palliative care approach for cancer patients, also implanted in 2005 at the School Hospital of the Federal University of Pelotas / RS.

Of the research carried out in specific units of PC, 100% of the international studies cover this specificity. It is worth considering that countries such as Portugal and Cuba already have a functional structure and a policy that instructs and makes possible the adequate execution of this philosophy of care.

In Portugal, for example, the family has the right, according to the PC Basic Law (Law no. 52/2012, of September 5th), to participate in the choice of the location of the PC, to receive information about the state if the patient wishes, to participate in decisions about the care that will be provided to the patient and the family and to receive objective and accurate information about the conditions of hospitalization. On the other hand, the teams have a work tool in home-based PCs, called the "Household Care Capacity Scale", with the objective of quantifying, in an objective and numerical way, the family's potential to assure PCs in their environment.[13-14]

Also, in these countries, the level of education of the family caregivers is greater, which facilitates the co-responsibility of the care and the proper decision making pertinent to the well-being of the family and patient. In Cuba, the first programs aimed at improving the quality of life of these patients emerged in the 1970s, with the medical and family health nurse program, whose main objective was to provide education to family members and patients in PC. [15-16]

In the studies carried out in general hospitals, there is an intimate relation of PC directly and exclusively related to patients with malignant neoplasias, and 69% of the studies attended this group of patients. It should be emphasized that this number is even greater when considering that the 21% of the remaining studies attended oncological patients and patients with chronic-degenerative diseases. This can be attributed to the considerable increase in malignant neoplasms in the world: the World Health Organization (WHO) estimates 300 million new cases and 200 million deaths within 25 years.[17]

Nursing leads both in national productions and in international studies. According to authors, [11] Nursing, as an integral member of the palliative multiprofessional team, can act both in the technical plane and in the understanding of human nature. Its training allows a focus of attention to the holistic needs of the patient and family planning and implementing actions that allow the individual to have maximum control over their life and illness.

It is possible to infer that, because Nursing is a profession characterized by care, in which professionals spend more time with patients, there is a tendency of this category to seek more information on the dynamics of this termination process. We also highlight the search for qualification, making it possible, through the studies, to present models / strategies, facilities / difficulties found in providing care to these families and patients.[18]

Psychology, however, seems to help in what, for people, is still a taboo: "to prepare for the nearness of death." Fear, anguish, and uncertainty about the unknown are issues specifically attributed to this professional category. However, the PC ideology requires the work of a multi-professional team in the care of these families / patients in order to contemplate all aspects of the human being effecting the PC proposal and considering that the individual and the family do not only experience changes / needs in its physical aspect, but also in the social, spiritual and psychological.[19]

For the family and also for health professionals, the understanding and acceptance of human terminality results from an understanding of the finitude, the relationship and the time in which they accompanied the patient and, consequently, his age. It seems that, culturally, the death of an elderly person is more easily understood and accepted (since it falls within the logical perspective of the natural cycle of life and death), but when it comes to a child it is more difficult the acceptance, because it escapes the inherent of living. The researches of this work were developed almost exclusively with young adults (82%). Only one article included palliative care for the elderly and three of them for children and adolescents.[11]

Family care is provided predominantly by females. The spouse, the children and grandchildren are among the main caregivers. [20-21] According to authors, [17] in all societies, women take on the main responsibilities of caring for children, the sick and the elderly, in addition to most of the domestic care. It is characteristic the care provided by the woman-centered family nucleus.

Within this perspective, only one family in all articles of the study hired a "non-family caregiver", which leads to the perception that, regardless of the financial situation, most families, even with difficulties, prefer to take care directly , not giving up "being with the patient". It is important to consider these data for the adequacy of care and support to patients and family members.

Family members used two types of family care strategies in the termination process. The first one corresponded to family strategies, with less emphasis on palliative care, in which situations and attitudes developed by family members usually not accompanied by a multi-professional team trained in PC. Within this process, human terminality encompasses a pathological state in which the treatment does not present curative responses, but a therapeutic remedy of relief allowing the needs / difficulties of the patients and families in this moment of doubt, uncertainty and fear.[14] Spiritual beliefs emphasize, in this category, as a means of confronting and understanding the termination process for both the caregiver and the patient. It is a coping mechanism of fear, loneliness and workload dedicated to the care of the loved one. And, to the patient, a hope for improvement.

It is also important to highlight the search of the family for being able to care by transforming the home into a comfortable place to take care of their loved one, assuming the responsibility of this care, enabling the caregiver to maintain their daily activities minimally and, patient, the maintenance of their personal and collective identity. It should be emphasized that the identity of this patient is in this environment, in his personal objects, still allowing, within the capacities of each one, to maintain his relationship with friends and neighbors in order not to lose the bond that already existed.[21-22]

In the second category, which encompasses family strategies with a greater emphasis on palliative care, in which one perceives an instrumental scenario with more technical elements of this specificity. There is a multi-professional team that specializes in this type of care, which provides assistance, taking into account all aspects of the human being, and prepares the family to play its role both in the hospital and in the home. This training of family caregivers goes beyond technical support, such as comfort, hygiene and pain control. The family's potential for decision-making is used, offering support throughout the termination process, including post-mourning.[11,23]

Care, to be considered as "palliative", should include, among its main characteristics, the provision of support to the family and the patient in the process of illness and mourning. In these care, four key instruments are included: symptomatic control, adequate communication, family support and teamwork.[20]

As can be seen, the strategies of care and coping of the termination of life process are not built instantly and rely on an imbricated range of relationships ranging from family scope to the support of a multidisciplinary health team. Such strategies go through the re-signification of the process of death and dying as inherent in one's own life. In this context, one arrives at a delicate territory of existence in which the culture of flight and fear of death presents itself as a challenge to be overcome by all. It is necessary to question why, in the western culture, one does not have a education directed to the death that gives a connotation of sense for it to exist?

When considering the research carried out, the importance of the role and work of the nurse in the care of these patients and their relatives is emphasized, emphasizing the possibility of being this professional the articulator of the integral care and, in particular, of the PC with the other health professionals . The selected studies confirm the initiative and commitment of the nurse in this purpose, that is, to observe, understand, act and present data of their work in favor of the qualification of the PC. These results are subsidies for the implementation of an overall care both as a model and as an incentive for the Nursing professionals themselves, as well as for those who provide assistance to this specific group.

CONCLUSION

It can be seen from the development of this study that family strategies do not require advanced technologies to be implemented. However, it is necessary to articulate in the intra-family, professional and health management spheres, which are supported in order to meet the needs presented daily in the course of terminal illness.

It is possible to decentralize the PC and provide it with quality in primary care. This enables continuous service, closer monitoring and ready to meet the difficulties that arise during this process. Not to mention that the health team knows this patient and family, their reality, limitations and potentialities.

There is a need to expand the training of professionals for this care profile, that is, within the palliative perspective. Therefore, it is appropriate to formulate a national palliative care policy in order to guide practitioners and the general population about care practices by standardizing the care and provision of services in these situations.

It is necessary to create new spaces that are not limited to a physical adequacy of health environments, such as outpatient and hospital, for example, to receive such patients. In order to meet this complexity, a "culture change" is pertinent in dealing with the termination process of life within the PCs.

The emphasis and discussion already within the scope of the academic training of future health professionals are indispensable and can be a profitable way, from the incentive to scientific production, in order to understand and provide multidimensional care as recommended in the philosophy of PC.

It is hoped that this study will contribute to the reflection on the care to the family and to the terminal patient by providing a care methodology that aims to strengthen them within this process that in itself is complex, arduous and tiring.

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