Family care strategies in relation to life termination

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; Tecnologías en Salud; Estrategias de Enfrentamiento.

RESUMEN

Objetivo: identificar las principales estrategias de cuidado por familiares que vivenciaron el proceso de terminalidad la vida de seres queridos, así como si los cuidados ejercidos en ese proceso contemplaron o no los cuidados paliativos y se abarcaron 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 descritores “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 Enfrentamiento.
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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.
<table>
<thead>
<tr>
<th>Nº</th>
<th>Year</th>
<th>Database and virtual library</th>
<th>Title</th>
<th>Area of pub.</th>
<th>Identified strategies</th>
<th>Level of evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>01</td>
<td>2015</td>
<td>SCIELO</td>
<td>Palliative care: challenges for caregivers and health professionals.</td>
<td>Psychology Brazil</td>
<td>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</td>
<td>VI</td>
</tr>
<tr>
<td>02</td>
<td>2015</td>
<td>SCIELO</td>
<td>Being cared for by a family member; the existential feelings of cancer patients.</td>
<td>Nursing Brazil</td>
<td>Link between patient and caregiver transcends the difficulties imposed by cancer.</td>
<td>VI</td>
</tr>
<tr>
<td>03</td>
<td>2014</td>
<td>SCIELO</td>
<td>Factors influencing end-stage and grief experience: perspective of the primary caregiver.</td>
<td>Nursing Portugal</td>
<td>Allow the end of life to happen at home. Act of caring inherent to the family.</td>
<td>VI</td>
</tr>
<tr>
<td>04</td>
<td>2014</td>
<td>SCIELO</td>
<td>Patient well-being followed in palliative care (CP): comparison between patient and family perspective.</td>
<td>Psychology Portugal</td>
<td>Spiritual belief and a good relationship with the family (affection, affection).</td>
<td>III</td>
</tr>
<tr>
<td>05</td>
<td>2011</td>
<td>SCIELO</td>
<td>Music in human terminality: the family members' conceptions.</td>
<td>Nursing Brazil</td>
<td>Music as a way to re-signify life, the environment of the patient and improvement in the interpersonal relationship.</td>
<td>VI</td>
</tr>
<tr>
<td>06</td>
<td>2011</td>
<td>SCIELO</td>
<td>The family as a therapeutic agent in palliative care.</td>
<td>Nursing Cuba</td>
<td>The qualification of the familiar caregiver in order to qualify care.</td>
<td>III</td>
</tr>
<tr>
<td>07</td>
<td>2014</td>
<td>SCIELO</td>
<td>Children and adolescents with cancer in palliative care: family experience.</td>
<td>Nursing Brazil</td>
<td>Faith and religious and spiritual belief.</td>
<td>VI</td>
</tr>
<tr>
<td>08</td>
<td>2015</td>
<td>SCIELO</td>
<td>The family's experience of the child and / or teenager in palliative care: fluctuating between hope and hopelessness in a world changed by losses.</td>
<td>Nursing Brazil</td>
<td>Maintenance and carrying out of daily activities. Staying at home as much as possible.</td>
<td>VI</td>
</tr>
<tr>
<td>09</td>
<td>2014</td>
<td>LILACS</td>
<td>Nursing in home palliative care: the look of the patient's family member with cancer.</td>
<td>Nursing Brazil</td>
<td>Formal social network¹ and informal¹ family support.</td>
<td>VI</td>
</tr>
<tr>
<td>10</td>
<td>2012</td>
<td>LILACS</td>
<td>Experience of professionals and families of patients in palliative care.</td>
<td>Psychology Brazil</td>
<td>Encounter, in religious beliefs, means of how to face and understand the terminality of life.</td>
<td>VI</td>
</tr>
<tr>
<td>11</td>
<td>2012</td>
<td>LILACS</td>
<td>Confrontation of the cancer patient and the family /</td>
<td>Nursing Brazil</td>
<td>Spiritual Beliefs.</td>
<td>III</td>
</tr>
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</table>
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 productions, 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
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.

REFERENCES


