Nursing Interventions for Family Caregivers in Home Palliative Care after the Relative's Death Integrative Literature Review

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Abstract

The family caregiver in palliative care is included in the focus of the nursing intervention. In a home context, the close relationship between the nurse and the family caregiver is more intense and remains after the relative's death. However, interventions directed in a structured way fade away, leaving a wide field of intervention open. Methodology: Conduct an integrative literature review in order to identify and describe the nursing interventions aimed at family caregivers in palliative care, after the relative's death. The research strategy included in the electronic databases CINHAL; Cochrane Database of Systematic Reviews, Nursing and Allied Health Collection, Medline and Scielo. The search was extended to RCAAP and Google. An article was also obtained directly from the author. Finally, 4 articles were included in this review. The analysis of the data resulted from a systematic process of identifying themes related to the phenomenon under study. Conclusions: Nursing interventions maintain communication between the bereaved nurse / caregiver, reinforce the bereaved nurse / caregiver relationship and support the bereaved caregiver's grieving process. This review emphasizes the need to develop support services in bereavement, particularly in the home context, as well as the need to enhance training under the theme of support in bereavement..

Keywords: Nursing Interventions; Family Caregivers; Palliative Care; Terminal Care

Introduction

To speak of palliative care is to speak of a human right. To find the origin of the palliative care movement and its mentor, it is necessary to go back to the 60s of the 20th century. In that moment, it was Cicely Sunders, who, having witnessed the scarcity of health care provided to patients at the end of their lives, claimed the need to develop a philosophy of care, that would respect the right for, not only the care, but also the patients's dignity in the process of dying The growth and expansion of the movement allowed the transition from the mere dealing with death at the end of life to the actual caregiving in the dying process, and it allowed the emergence of the so called palliative care. Professor Lobo Antunes defines palliative care in the preface to the Palliative Care Manual as the "twilight medicine, that is, the medicine that takes care of those in whom the light of life, little by little, goes out (…) it is the medicine of the comfort of the spirit, the prudent relief of suffering, the encounter with the other, the communal effort, the tenacious preservation of dignity."[2].

One of the most recent definition of the IAHPC (International Association for Hospice and Palliative Care 2018) describes palliative care as a "holistic, active care provided to individuals of all ages with intense suffering and serious illness, especially aimed at those

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near the end of life. It aims to improve the quality of life of sick people, their families and caregivers". The reference definitions of the WHO (World Health Organization) and the CAPC (Center for Advance Palliative Care-USA) further contribute to a broader vision of care that includes a global and a comprehensive approach centered on the sick person and his/her family in its multiple aspects [4,19].They recommend palliative care to be carried out by a multidisciplinary team, and to be extended in its supporting component for the family caregiver even after the bereavement, throughout the mourning period. Those definitions emphasize the fact that palliative care intervention meets "a set of needs determined by the suffering of advanced disease and the multiple losses that it determines, and not based on a prognosis or a diagnosis" [14]. The last decades have seen the development of palliative care, and it's inclusion in the clinical and health planning (for individual intervention but as well as a public/instituinalized level). In fact, the evolution of the concept and the growth of its acocompanying research imposed the development of a philosophy of palliative care in the clinic and the planning of care. It should also be noted that this type of health care targets people with cancer and non-cancer diseases, as well as people at the end of life (last 12 months of life), people in the terminal phase (by definition, with 3 to 6 months of life) or people in an agony phase (with hours or days to live) [14]. Classically, the structural areas in palliative care are considered to be symptom control, adequate communication, family support and teamwork. However, it may be said that the importance assigned to each area is interdependent with the others, in a perspective of equality, without one being more important than the other [13].

In relation to the family member and the sick person, the philosophy of palliative care is both integrative and aggregative in relation to the family. Therefore, the family is a caregiver and essential in supporting the sick person, but at the same time it is a recipient of care.

According to Moreira, the family is the basic unit in which we develop and socialize; it is in the family that emotional support and security are provided through love, acceptance, interest and understanding. Faced with the illness of one of its members, the family is faced with a change in its functioning and organization. It can be said that taking care of the sick person is also taking care of his/her family, i.e. the person and its family are seen as a dyad or unit to take care of, to intervene in. In this perspective, it is essential to identify the person who is closest to and most involved in caring for the sick person in the family, the family caregiver [11]. This process of interaction with the family is supported by an open, dynamic and multidirectional communication approach [18]. Identifying the family caregiver allows the team to integrate him/her in the intervention plan with a view to strategies defined by Neto: (1) education/information; (2) emotional support and help in the reorganization of the caregiver/family in the prevention and treatment of the grieving process [14].

After the death of the sick person, it highlights how the caregiver/family will experience the loss. For a healthy adaptation to loss, it is crucial to see how each family member relates to the others. In general, the resilience of families is big enough to adapt to the loss, but for some families, characteristics of morbidity risk may arise after the loss that should be targeted by intervention [2]. However, it is necessary to take into account the caregiver within the family, who requires a careful look given his/her involvement in the entire disease process. The intervention with the caregiver, according to Barbosa, intersects the moment of discussion of the prognosis, planning of future care (advance guidelines), dealing with the conflict, suspension of life support, considering cultural and spiritual concerns and finally the discussion about grief and loss [2]. All this involvement requires preparation and support from the team with a special regard to the mental health of the caregiver and his adjustment to the experienced situation of caring for a sick anddying person. Caring for a terminally ill person is a challenge for both the family and caregiver. It is an act that requires dedication and time, the care process represents an appeal to professionals to know how to be and how to listen, accompany and support [9]. In the experience of caring for a sick person in palliative care, the family caregiver is involved in the team, with which he/she will share anxieties, insecurities, fears and achievements. In the course of the disease process, the caregiver builds a total connection with the team. The therapeutic alliance developed between the team and the caregiver will reinforce the therapeutic alliance and tranquility in decision-making.

As part of the team, nurses represent a constant presence in the therapeutic relationship, being in many situations case managers and therefore links between the sick person/caregiver/family. According to Nunes, "establishing a helping relationship does not mean giving solutions or indicating strategies (...) it means, rather, creating relational conditions that allow the Other (the one who asks) to discover the path that, in line with his/her subjectivity, allows him/her to be creative and coherent in the solutions he/she discovers to overcome difficulties or problems." In palliative care, the context is marked by vulnerability, the relationship between the nurse and the caregiver

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takes place in response to and expression of the construction of this path of harmony [17]. In addition, Nunes states that "the care process is constituted as an interpersonal relationship, in which the nurse's competence is based on his/her commitment to care of the other and on the intention to affirm the other as a person, thus setting up a protective care [16]." It is also important to clarify the concept of the nursing intervention, as it represents an action, associated with knowledge, which can enhance the intervention and simultaneously develop new skills, influencing action patterns, as well as better understanding the nurse-patient interaction and the impact that it can have on both, with a focus on patient's well-being [22]. In a hospital context, the person/caregiver/family is in an environment of greater physical proximity to the team, with the presence of a nurse 24 hours a day. However, the literature says that the preferred place of the sick person is his/her home [7][8][10]. In the home context, the physical presence of the team is not permanent, which could be an obstacle, although this assumption is disproven by the literature that states a stable and trustful connection [7].

In the home context, the relationship between the sick person/caregiver/family and the nurse becomes even closer at first. Nurses become witnesses of the entire care process, which after the death of the patient serves as a real confirmation of everything that has been experienced. However, the caregiver's vulnerability emerges in the intensity of the process experienced at home which requires and calls for an intervention directed by the team, namely the nurse, and so, being an enhancer of peaceful grief "loss integrated in autobiographical memory, thoughts and memories about the deceased are not worrying or disturbing to other activities that now progressively occupy more time than those related to the deceased [1,7,8]." After the death of the patient, nurses can develop general interventions in immediate and/or structured support within the team based on the basic principles of grieving support/counsellingidentified by Barbosa: accompanying rather than treating; emotional containment, rather than intervention or interventionism, prudence in psychological as well as biological interventions, and proposing microsocial changes [1]. Not forgetting that each grieving process is unique and singular.

According to Barbosa, the narrative approach is a means of relating to the other and communication is the central tool for this to happen, building up on the model of relational ethics [2]. This model assumes a relational narrative in the clinical relationship, emphasizes the mutual commitment of those involved in a cooperative creation, based on the awareness of mutual vulnerability. This thought, based on Narrative Medicine, leads to care centered on the relationship with the person. According to Charon, Narrative Medicine is practiced with the narrative competence to recognize, absorb and interpret suffering, through the history of the disease, the vulnerability of those we care for, those we work with and ourselves. It implies to act in consonance [5].

In short, the approach to the family includes a careful look at the family caregiver who is in the home context more exposed to vulnerability. In the relationship with the nurse, the family caregiver consolidates his/her experience of caring. The focus will be to identify the impact of nursing interventions that target family caregivers in palliative home care after the family member's death.

Objective

We performed an integrative literature review to identify nursing interventions aimed at family caregivers in home palliative care, after the death of the family member; to describe the nursing interventions aimed at family caregivers in home palliative care after the family member's death.

Question (PICo): In relation to family caregivers, what are the nursing interventions directed at home PCs after the family member's death?

Methods

To respond to the proposed objectives, the purpose of carrying out the integrative literature review is followed to gather and synthesize results of studies carried out, through different methodologies, to deepen the knowledge of the chosen topic [23]. The keywords, or descriptor, were selected from the question, after confirmation in the DeCs and MeSH platform: (Nursing intervention) AND (Care* OR Palliative treatement) AND Terminal care (Nursing interventions) AND (Caregivers OR Palliative Care) AND Terminal Care [6].

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Data Bases

CINHAL; Cochrane Database of Systematic Reviews, Nursing and Allied Health Collection, Medline and Scielo. The search was extended to RCAAP and Google.

Inclusion and exclusion criteria

Studies in the context of palliative care in the home context were included (the place of care was understood to be the home/palliative care unit/hospice). As for the participants, the inclusion criterion was bereaved caregivers accompanied by nurses. Studies whose participants were 18 years old or younger were excluded, so were articles which were not written in English, Spanish or Portuguese. In this review, there was no limitation in regard of the time period.

Study selection

As a result of the research carried out, 192 studies were identified. The first step of selecting the articles allowed the exclusion of all articles repeated in the different databases used. The second stage consisted of an exhaustive reading of the title and abstract, selecting the articles relevant to the issue under study. Of these, 26 were selected for the title. After reading the abstract, 2 were excluded, as they did not meet the inclusion criteria for the participants. 24 articles were read fully and 22 were excluded for not meeting the inclusion criteria. Two articles were selected, to which we added one provided by the author and another obtained in the extended Google research was added (there were no articles found in the RCAPP that met the inclusion criteria). The Oxford Centre for Evidence-Based Medicine was used as a reference to establish the level of evidence. Data analysis resulted from a systematic process of identification of themes related to the phenomenon under study, allowing us to assess the following characteristics of each article: identification of the publication, year of publication and authors, study methodology and results/conclusions expressed by the author, as can be seen in diagram 1, this review illustrates 4 articles [20].
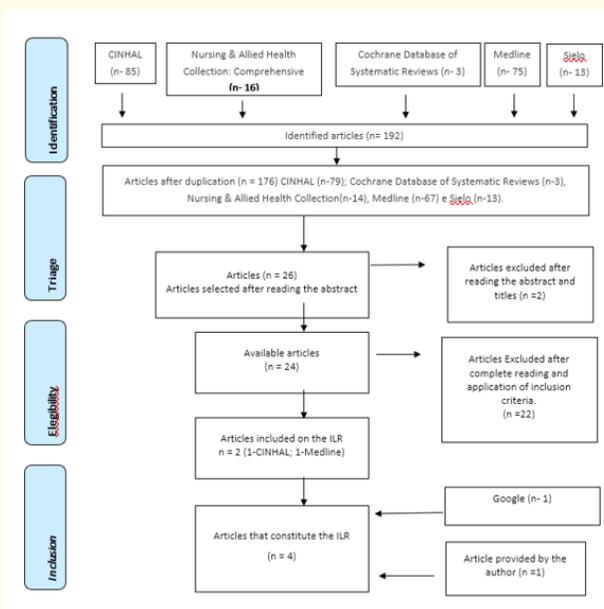
Selection

Diagram 1: *Seletion of articles for the Integrative Literature Review (ILR).*

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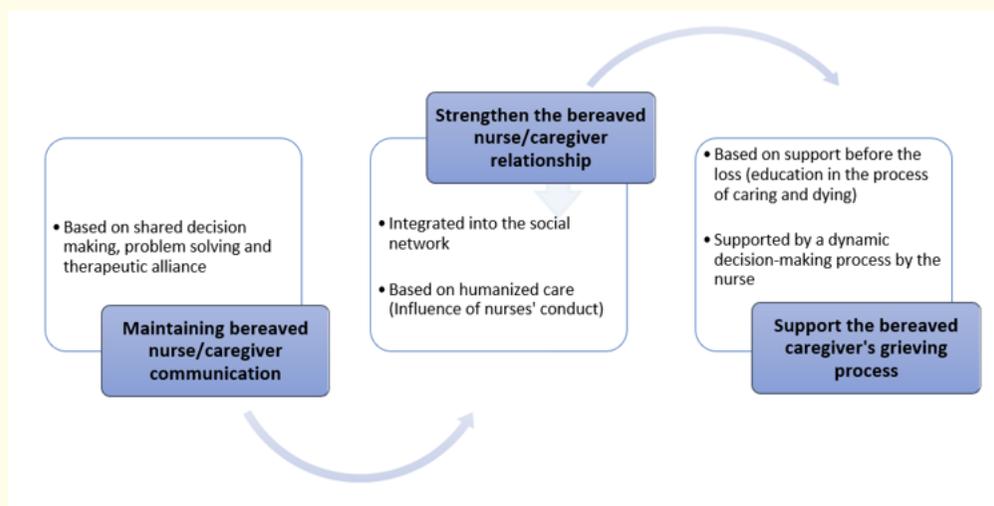|	Level of Evidence	Methodology/ Data collection method/ Analysis method	Sample	Objetive	Results
Holdsworth LM; 2015; UK	N4	Qualitative descriptive/ structured interviews/ content analysis according to Snape and Spencer	270 caregivers referred by a hospice in South West England, 44 were selected	Exploring how caregivers conceptualize the "good death" and what impact their conceptualization can have on them.	The results suggest that health professionals have a multidimensional role, which exceeds medical and nursing support, and makes them become an integral part of the social support network shaping the caregivers' experience. The findings underline the importance of the characteristics and actions of health professionals in trusting in the act of caring and in supporting grief.
Pazes, M.; Nunes, L.; Barbosa, A. ; 2014; Portugal	N4	Qualitative descriptive and exploratory/ structured interviews/content analysis	7 female caregivers, aged between 34 and 73 years, intentionally chosen, accompanied by nurses who make home visits.	Knowing the influence of the nurse's conduct, attributed by the main caregiver, on the experience of the disease process in the terminal phase and of mourning the death of a close person.	The results point to the importance attributed by caregivers to communication with nurses, valuing information about the reality of the situation experienced and reinforcing realistic hope. Fundamental aspects emerged, such as the care process (factors influencing the performance and functions of the caregiver's role) and the grieving process (how the caregiver manages the loss). The influence of the nurse's conduct (in knowing how to act in crucial moments) appears as a determinant for the relationship of trust with the caregiver.
Nietsche, E.; Vedoin, S.; Bertolino, K.; Lima, M.; Terra, L. ; Bortoluzzi, C.; 2013; Brasil	N4	Qualitative, descriptive and exploratory/ semi-structured interviews/ content analysis according to Bardin	4 family caregivers and 5 health professionals nurses who make home visits	Identifying the perception of the health team and caregivers of terminally ill patients in the home context, about the care provided in the process of dying and death.	The results point to the need for humanized care – the relational dimension associated with the clinical dimension, emerging the need for respect, communication and understanding. The relationship with the nurse appears as a focus of teaching, safety and tranquility. The home appears as the place of greatest connection between the patient and the family, support for terminally ill patients focuses on comfort, relief from pain and suffering.
Brownhill, S.; Chang, E.; Bidewell, J.; Johnson, A.; 2013	N4	Qualitative, grounded theory methodology	10 nurses who make home visits	Exploring the decision-making process regarding support in grief for relatives of patients accompanied in palliative care. .	The results show the importance of the nurses' role in supporting the bereaved family/ caregiver and reveal the construction of a decision-making model for nurses. This model highlights the interaction between communication, the circumstances of the context, the psychosocial variant of the bereaved, the characteristics of the nurses, the workload, the support available to the nurses and the bereaved, and the elements inherent to the visit..

Table 1

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Diagram 2: *Nursing interventions for family caregivers in home palliative care after the relative's death.*

Results and Discussion

After reading the selected studies for this review and subsequent grouping of information, it was possible to identify three areas of nursing intervention aimed at family caregivers in palliative care after the death of the family member: (1) maintaining the nurse/bereaved caregiver communication; (2) reinforce the nurse/bereaved caregiver relationship and (3) support the bereaved caregiver's grieving process. The areas of nursing intervention are described below.

(1) Maintaining bereaved nurse/caregiver communication

In the selected studies, communication appears as a key aspect for caregivers, as a means of preparation for the awareness and imminence of death [11]. Communication is a therapeutic tool for problem solving and decision making, which consolidates the therapeutic alliance between caregivers and health professionals, namely nurses [15,21]. The importance attributed by caregivers to communication with nurses, values information for the reality of the situation experienced and reinforcement of realistic hope, as well as the availability to be present and respond [21].

The nurses' position towards bereaved caregivers is significant, related to the relationship already established during the follow up palliative care visits. Communication stands out between nurses and bereaved caregivers as a therapeutic tool in building trust. Thus, maintaining communication, based on previous experience of joint decision-making, problem solving and therapeutic alliance is a structuring and facilitating intervention in the grieving process of bereaved caregivers in palliative care [3,11,15,21].

(2) Strengthening the bereaved nurse/caregiver relationship

In this review, the relationship established between nurses and family caregivers naturally evolves to a supportive intervention with a calming and predominant effect on the grieving process of the bereaved caregiver [3,11,15,21]. The established relationship reaches beyond the clinical setting, as it also consists of becoming part of the caregivers' social network. The role of nurses is multidimensional, which reinforces the impact on the relationship with caregivers in the transition to the grieving process. The influence of nurses' conduct, in terms of their know-how, can enhance the caregivers' confidence and has a significant impact on the experience of the disease

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and mourning process. With regard to the characteristics of the established relationship, respect, dialogue and understanding stand out, which can be though easily forgotten at the expense of technical aspects [3,11,15,21]. This study identifies the dynamism of the relationship, enhanced by the level of involvement of the nurse with the family/caregiver. The relationship starts out being professional and becomes more connected and intimate over time. It is more intense the more involved/connected the nurse is with the family/caregiver [3]. Thus, strengthening the nurse/bereaved caregiver relationship is an intervention that clearly appears after the death of the family member [3,11,15,21]. In palliative care, this is elevated to the perspective of support in the grieving process, emphasizing an already existing relationship that can facilitate the restoration of the self and a peaceful grieving.

(3) Support the bereaved caregiver's grieving process

Supporting the grief process of the bereaved caregiver is recurrent in studies and appears to be linked to the interventions described above. The selected studies show how the caregiver's experiences regarding care and the end of life are marked by the support of nurses, determining tranquility in the face of the loss of the family member [3,11,15,21]. According to the findings of Pazes Nunes and Barbosa, the process of caring for the bereaved caregiver is a determinant of the grieving process, although with greater impact in the home context. Education in the care process and preparation for the care of the terminally ill emerges as an essential aspect to work out with the caregiver, focusing on safety and reassurance [15,21]. The role of the nurse in the grief process of the bereaved caregiver is designed in advance, so that after the death, a structured support and assistance begins, which represents a dynamic decision-making process for the nurses [3,11,15,21]. The study by Brownhill, Chang, Bidewell, and Johnson clarifies this process of nurse/bereaved caregiver interaction, from the nurse's point of view, showing the mode of interaction through home visits to monitor and evaluate the grieving process of the bereaved family/caregiver [3]. Also in this study, the complexity of the role of nurses who give bereavement support in the home context is identified, with a focus on their decision-making process. The results show that their decision making process is dynamic, interactive and multifactorial between communication, the circumstances of the context, the psychosocial variant of the bereaved person, the nurses' characteristics, the workload, the support available to nurses and to the bereaved person and the elements inherent to the visit.

Thus, the intervention of supporting the grieving process of the bereaved caregiver is characterized by a proximity to the caregiver prior to death and sharing the experience of loss with a positive impact on the grieving process of the bereaved family/caregivers facilitating the restoration of the self and the realization of peaceful grief [3,11,15,21].

The identified interventions to maintain the nurse/bereaved caregiver communication, to strengthen the nurse/bereaved caregiver relationship, and to support the bereaved caregiver's grieving process are intertwined, as if contiguous, as can be seen in the following diagram.

Conclusion and implications for nursing practice

This review identifies nursing interventions aimed at family caregivers after the death of the family member, underlining the vulnerability of palliative care in the home context. The articles examined in this review identify 3 areas of intervention: (1) maintaining the bereaved nurse/caregiver communication, (2) strengthening the bereaved nurse/caregiver relationship, and (3) supporting the bereaved caregiver's grieving process. These interventions are described in a continuous manner, i.e. the communication and the relationship that was previously developed in the care process is meant to be maintained and strengthened through the support for family members in the mourning process. The transversality of these interventions, that can be reconstructed through their intertwined and interdependent nature, should be highlighted, i.e., through communication, the cornerstone of a therapeutic relationship, the relationship between the nurse and the bereaved caregiver is consolidated, which will subsequently facilitate the necessary support in the grieving process of the bereaved caregiver, promoting a peaceful bereavement processes.. In palliative care, this is elevated to the perspective that support in the grieving process is integrated into the philosophy of care.

The findings underline the need for the development and expansion of palliative care in the home context, as well as the emergence of the structuring of nursing interventions aimed at the family caregiver after the death of the family member, especially for support in

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mourning. This review emphasizes the need to develop support services in mourning, namely in the home context, as well as the need to enhance training under the theme of support in mourning.

For future studies it is suggested to deepen this aspect, as well as the impact of nursing interventions after the death of the family member, namely in the grieving process of the family caregiver.

Bibliography

1. Barbosa A and IG Neto. "Manual de Cuidados Paliativos". *Lisboa. Faculdade de Medicina de Lisboa Centro de Bioética*, (2010).

2. Barbosa A., *et al.* "Manual de Cuidados Paliativos". *Lisboa. Faculdade de Medicina de Lisboa Centro de Bioética* (2016).

3. Brownhill S., *et al.* "A decision model for community nurses providing bereavement care". *British Journal of Community Nursing* 18.3 (2013):133-139.

4. CAPC (Center for Advance Palliative Care-USA) (2014).

5. Charon R. "Narrative Medicine: Honoring the stories of illness (2006).

6. DeCS (Descritores em Ciências da Saúde), (2019).

7. Ferreira F., *et al.* "Validação da escala de Zarit: sobrecarga do cuidador em cuidados paliativos domiciliários, para população portuguesa". *Cadernos de Saúde* (2010).

8. Ferreira N., *et al.* "Cuidados paliativos e família". *Rev. Ciênc. Méd., Campinas* 17.1 (2008): 33-42.

9. Guarda, H., *et al.* "Apoio à Família in Manual de Cuidados Paliativos. Lisboa". *Faculdade de Medicina de Lisboa Centro de Bioética* (2010): 749-760

10. Gomes B., *et al.* "Estudo Epidemiológico dos Locais de Morte em Portugal em 2010 e Comparação com as Preferências da População Portuguesa". *Acta Med Port* 26.4 (2013): 327-334.

11. Holdsworth LM. "Bereaved carers' accounts of the end of life and the role of care providers in a 'good death': a qualitative study". *Palliat Med* 29 (2015): 834-841.

12. Moreira I. "O Doente terminal em contexto familiar – uma análise da experiência de cuidar vivenciada pela família ". *Coimbra* (2001).

13. Neto I. "A conferência familiar como instrumento de apoio à família em cuidados paliativos". *Rev Port Clin* 19 (2003): 68-74.

14. Neto I. "Princípios do Controlo de Sintomas, um pilar dos Cuidados Paliativos". *Acta Med Port* 2009 (2017).

15. Nietsche E., *et al.* "Equipe de saúde e familiares cuidadores: atenção ao doente terminal no domicílio. *Revista de Enfermagem Referência* III Série 10 (2013): 55-62.

16. Nunes L. "Fundamentos éticos da deontologia professional". *Ordem dos Enfermeiros* 31 (2008): 33-45.

17. Nunes O. "A Pessoa como Centro -Revista de Estudos Rogerianos 3 (1999): 59-64.

18. Querido A., *et al.* "Comunicação in Manual de Cuidados Paliativos, Lisboa. Faculdade de Medicina de Lisboa Centro de Bioética (2010): 461-486.

19. OMS (Organização Mundial da Saúde), (2002).

20. Oxford Centre for Evidence-Based Medicine. *Levels of evidence* (2009).

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21. Pazes M., *et al.* "Factors que influenciam a vivência da fase terminal e de luto: perspetiva do cuidador principal". *Revista de Enfermagem Referência, Série* 3 (2014): 95-104.

22. Sapeta P and Lopes M. "Cuidar em fim de vida: factores que interferem no processo de interacção enfermeiro doente I4 (2007).

23. Soares C., *et al.* "Revisão Integrativa: Conceitos e Métodos utilizados na Enfermagem, Revista Esc Enfermagem USP". 48.2 (2014): 335-345.