

# Needs of End-of-Life Patient's Caregivers, in Terms of Nursing Care: Systematic Review of the Literature

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## Abstract

**Aim:** This article aims to identify the needs for nursing care of end-of-life patients' caregivers and also to enounce nursing interventions, by using a systematic review of the literature.

**Methodology:** The PI[C]OD method has been used, and a search in EBSCO (CINALH, MEDLINE) has been conducted by using keywords and searching full texts, from 2000 until December 2010, resulting in 325 articles in total.

**Results:** The end-of-life patients' caregivers' needs identified through this systematic review were: preparation for mourning, desirers' recognition and fulfilment, communication, establishment of a trustful relationship with a sense of security, caregivers involvement in care, training, resting needs, needs for information, emotional and spiritual needs.

**Conclusions:** Caregivers have different needs that require personal intervention from the nursing team, which is fulfilled through the establishment of a relationship based on trust, and considering that each caregiver has unique characteristics and personal attributes. The caregiver should be involved in care process, enabling knowledge and skills.

**Keywords:** Caregiver; Needs; Nursing

## Introduction

In providing care to terminal patients, the importance of nursing presence and caregiver support throughout their grieving process becomes highlighted. In fact, these caregivers face an enormous emotional suffering and, at the same time, they should be able to join forces to help their relative who is terminally ill. Therefore, the caregiver should be informed about the disease progress, alerted to possible symptoms and to the development of the final stage [1]. Taking the complexity of the experiences lived by family caregivers of persons in end-of-life into account and also considering nursing care in order to respond to their needs, we enounce the following research question: "Which are the nursing care needs of the end-of-life patients' caregivers?". Thus we aim to identify these needs and understand how the nurses can respond to them in their practices [2].

Death is a complex reality. There was a beginning, for each of us, and there will be an end [1,2]. The person, becoming aware that death is imminent, experiences very strong feelings and emotions of loss, fear and anxiety, having the need to be heard, understood and supported [3]. In order to answer to these needs it has been developed the so called "modern movement of palliative care", whose core components are: symptom control; psychological, spiritual and emotional support; caregivers' support and also during grief; and interdisciplinarity [4]. The dynamic of the palliative care units is centered both on patients and on their cares as well, being these cares considered simultaneously as providers and as receivers of the health care professionals' interventions. The care process is usually extended throughout grief, by giving emotional and psychological support [4,5]. The diagnosis of a serious illness and the certainty of death cause a break in the family balance, which has consequences both on family's functioning and structure, generating tension and requiring an adaptation process [3-5]. Furthermore, the family caregiver helps the patient to cope and to adapt to the situation, by being able to provide support [6],

maintaining a true and affectionate communication, dealing with the crises that is occurring and, finally, making a healthy grief [7]. The family caregiver should be involved in the care process, by investing in the communication and in the establishment of a partnership that's interactive, dynamic, available [8], sharing responsibilities with the nursing team, raising his capacities and potentials as a resource [9]. The major caregiver is the person, family caregiver or not, that provides the most care to the person in situation of dependency, without receiving any financial compensation [10], reconciling with their own professional, marital, social and familial responsibilities [8]. Caring for a terminal ill person is a demanding task, which may be exhausting both physically and emotionally [9], implying physical, psychological, social and financial costs. However it is often referred by the caregivers as a unique and rewarding experience, which may promote personal and spiritual development [11]. Therefore, it is relevant to understand the needs of end-of-life patients' caregivers, in terms of nursing care.

In the present study we use the words "caregiver" and "family caregiver" as being the persons who provide care to those who need supervision or assistance in illness or disability. They may provide the care in the home, in a hospital, or in an institution. Although caregivers include trained medical, nursing, and other health personnel, the concept also refers to parents, spouses, or other family members, friends, members of the clergy, teachers, social workers, fellow patients<sup>1</sup>.

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<sup>1</sup>2012 MeSH, MeSH Descriptor Data - National Library of Medicine - Medical Subject Headings.

## Materials and Methods

In order to respond to the outlined goal, a research question has been enounced considering the criteria of the PI[C]OD format [12]: Which are the needs of end-of-life patients' caregivers, in terms of nursing care?

A research in electronic databases, namely CINAHL Plus with Full Text and MEDLINE with Full Text, both through EBSCO, has been conducted in order to obtain a broader understanding of this phenomenon. The keywords used were previously validated by descriptors of the United States of National Library of Medicine, National Institutes of Health, and searched with the related guidance: [(Palliative Care OR Terminal Care OR Terminally Ill Patients OR Family) AND (Nursing OR Nursing Care OR Nurse) AND (Needs Assessment OR Nursing Care Needs OR Needs)]. The articles were searched in full text and all the articles published between 2000 and December 2010, have been considered, resulting in a total of 325 articles. The systematic literature reviews considers it should include the evidence of the last 5 years, but we consider the time period of 10 years, because of a greater coverage compared to the existing knowledge on the subject in question [12]. In order to evaluate the levels of evidence we used the following six levels of evidence: Level I - Systematic reviews (meta analysis / guidelines for clinical practice based on systematic reviews); Level II - Experimental study; Level III - Quasi experimental study; Level IV - non-experimental studies; Level V - Qualitative study / review of the literature without systematic meta-analysis; Level VI - Opinions of respected authorities / Consensus panels [12].

As inclusion criteria, we privileged articles that were focused upon clinical practice and that highlighted their results among their applicability and impact on health outcomes. As exclusion criteria we considered those articles in which methodological procedures were described in an unclear manner, and also those articles that appeared repeated in the two databases, dated before 2000 and those without correlation with the object of study. The methodological course carried out is shown in the figure 1.

## Results

The table 1 gives the list of articles that were selected and considered relevant to the study in question.

Protocol - EXAMPLE	
↓	<b>Identification:</b>
	<ul style="list-style-type: none"> <li>Number of articles identified in the database search (CINAHL, MEDELINE) - 325</li> <li>Number of articles identified in full text, years 2000 to 2010 - 241</li> </ul>
	<b>Screening:</b>
	<ul style="list-style-type: none"> <li>Number of articles duplicate and removed - 23</li> <li>Number of articles selected (title and summary) - 107</li> <li>Number of articles excluded (title and summary) - 111</li> </ul>
	<b>Inclusion Criteria (Full reading):</b>
	<ul style="list-style-type: none"> <li>Number of full-text articles with inclusion criteria - 19</li> <li>Number of full-text articles without inclusion criteria - 88</li> </ul>
	<b>Included article (level of evidence):</b>
	Level III - 5; Level IV - 14.

Figure 1: Process of article survey and selection - Search on CINAHL, MEDLINE - Period 2000-2010.

## Discussion

The analyses of these articles contributed to give an answer to our research question, since, explicitly or implicitly, mostly address the needs of end-of-life patients' caregivers. The three major concerns to consider when improving the quality of palliative care are: emphasis on spiritual care, caregiver involvement and education of professional ethics [13]. In order to support and early prepare the person and the caregiver to the final trajectory of the disease, it is recommended a better education of the person and family as well as better collaboration between multidisciplinary team members [14-16] emphasizing the importance of communication improvement between the caregiver and health professionals, namely regarding treatment decisions [2].

The involvement of caregivers in providing physical care (hygiene, nutrition, elimination, alternating decubitus) and in symptom control, as well assisting or replacing the person in carrying out activities which formerly were performed by her/him, should be considered [7]. Furthermore, assuming the role as a caregiver implies the need for his/her abilities to perform like that, which points to some factors that might help caregivers to perform this role: support provided by the palliative care team, previous experience, quality of the relationship with the person in end of life and living one day at a time [11]. On the other hand, the obstacles when preparing the caregiver include sudden need to perform this role, the responsibility associated to it, communication difficulties with the physicians, not being included on the treatment plan discussion, the unpredictable nature of this role, the physical and psychosocial impact and the frustration while waiting death [2,3].

When providing information to caregivers, some basic elements should be considered: rights and options; demands; dealing with stress and emotional implications of their own health care; promote encouragement and optimism; who to contact for counseling and help; getting support from family and friends, having someone to share their experience; manage the financial implications; rest regularly; access to skilled professionals; how to administrate therapy; how to promote the person comfort; practical aspects of the caregiver's role (use of equipment, hygiene and nutrition); prepare a death at home; discussing death and "dying", referring to what to expect during the stage of death, the preparation of grief; and potentially positive aspects of care giving [19,20].

Caring for a person in end of life is a difficult experience at a physical and mental level, endangering the health and harmony of the caregiver. Therefore the moments of rest are also considered to be important, namely by providing a pause from the responsibility assumed as a caregiver, which acts as a return to normal life [6-11].

The experience of caring a person in end of life is a very significant one, encompassing the psychological, emotional and spiritual dimensions. The uncertainty and fears about the future and lost are the most common psychological concerns of caregivers of people in end of life [15]. On the other hand, these caregivers show unsatisfied emotional needs and are not prepared to make decisions concerning terminal treatments due to a lack of informational and emotional support by the professionals [16]. Their spiritual needs are also emphasized, with the collaboration of the chaplain or spiritual assistant, who is capable to assess and meet them, as well as the spiritual needs of nurses [16]. The following strategies emerged in order to support the caregiver: promotion of an effective communication, the caregiver involvement in care provision, negotiation of special needs, optimal control of pain and other symptoms management provision, existential support, preparing the caregiver for the death, caregiver's participation in the death process and support during the grieving process [9].

Articles includes / Methodology / Participants	Results
<p><b>Methodology:</b> Qualitative approach. Descriptive study [17]  <b>Levels of evidence:</b> IV  <b>Participants:</b> 28 Relatives of people with dementia in a hospital wards</p>	<p>5 themes describe the context of family's decision making: emotional effect, confrontation of the life history, the two faces of death (tragedy versus blessing), values and goals of palliative care and the unrecognizable path of death. These continuously revealed an unsatisfactory informational and emotional support by a professional.</p>
<p><b>Methodology:</b> Qualitative approach. Structured interviews [20]  <b>Levels of evidence:</b> IV  <b>Participants:</b> 62 Team members of community nursing</p>	<p>In the community it's essential that the nurse knows the caregiver through an attitude of openness and sensitivity.</p>
<p><b>Methodology:</b> Quantitative approach. Structured interviews [9]  <b>Levels of evidence:</b> III  <b>Participants:</b> Nurses, nursing assistants and family members. Total of 259 participants</p>	<p>Death is not just an individual event but it also evolves the caregiver. It should focus the attention of the professionals in the family, since it suffers from the disease of the family member and remains always by his side.</p>
<p><b>Methodology:</b> Qualitative approach. Group discussion with a moderator [11]  <b>Levels of evidence:</b> IV  <b>Participants:</b> 8 Ex-caregivers and 6 current caregivers at the person's house whit advanced stage cancer, and 7 community nurses of palliative care</p>	<p>The factors that help caregivers to fulfill their role is support, previous experience, the relationship with the person who's dying and living one day at a time. The guidance and support should be early provided, responding to expressed individual needs by the caregiver, using different means, documenting, evaluating and planning.</p>
<p><b>Methodology:</b> Qualitative and quantitative approach. Questionnaire and narratives [7]  <b>Levels of evidence:</b> IV  <b>Participants:</b> 538 Nurses</p>	<p>The 3 most important issues identified by nurses in palliative care are: inability to meet the spiritual needs, loneliness and pain control.</p>
<p><b>Methodology:</b> Qualitative and quantitative approach. Semi-structured interview [14]  <b>Levels of evidence:</b> IV  <b>Participants:</b> 45 Family caregivers of patients whit cancer</p>	<p>The caregivers' needs are multiples and complexes, requiring an evaluation for interventions' planning. Nurses should refer the caregivers to support services, such as social workers, psychologists, support groups, counseling and bereavement.</p>
<p><b>Methodology:</b> Qualitative approach [18]  <b>Levels of evidence:</b> IV  <b>Participants:</b> 25 Community Health Nurses</p>	<p>There were identified four crucial themes: communication between nurse and patient, family as a fundamental element of care, symptoms control and emotions.</p>
<p><b>Methodology:</b> Qualitative and quantitative approach. Semi-structured interviews [13]  <b>Levels of evidence:</b> III  <b>Participants:</b> 25 Family caregivers of a person admitted into the institution (mental hospital)</p>	<p>It was found that the cares to significant others on end of life are demanding and difficult. Since most of caregivers have an arduous work, both physically and mentally, stands the need for them to rest.</p>
<p><b>Methodology:</b> Qualitative and quantitative approach. Semi-structured interviews and <i>Palliative Care Practices</i> Questionnaire. [15]  <b>Levels of evidence:</b> IV  <b>Participants:</b> Health professionals and others professionals involved in palliative care</p>	<p>The strategies to support the family include: promoting an effective communication, involvement in care, negotiation of special needs, provide an optimized control of pain and other symptoms, provide existential support, preparation for death, allow the participation in the death process and provide support for the mourning.</p>
<p><b>Methodology:</b> A qualitative study <i>cross sectional</i> [10]  <b>Levels of evidence:</b> III  <b>Participants:</b> 19 Members of 17 families of people with cancer and 10 nurses specialized in palliative care working on the same geographical area.</p>	<p>The physical care implies that the family helps or replaces the ill person on carrying out activities which formerly performed alone, such as hygiene, elimination, switching position and nutrition. Nurses play a key role on the family's educating and training, especially in the use of technical aids and symptoms control.</p>
<p><b>Methodology:</b> An exploratory descriptive study. Semi-structured interview. [8]  <b>Levels of evidence:</b> IV  <b>Participants:</b> 17 Senior nurses with experience in palliative care and acute care centers, and 5 community centers</p>	<p>The study highlights the need for a better education of the patient and family, and collaboration between members of the multidisciplinary team in order to provide early support and preparation to them for the final trajectory of the disease.</p>
<p><b>Methodology:</b> Qualitative approach. Written inquiry. [16]  <b>Levels of evidence:</b> III  <b>Participants:</b> 108 Nurses who participated in two courses about the end of life.</p>	<p>Emerges the need for collaboration with the chaplain to assess and meet the spiritual needs of the patient, family and nurses.</p>
<p><b>Methodology:</b> Quantitative approach. Professional End-of-life Care Attitude Scale [19]  <b>Levels of evidence:</b> III  <b>Participants:</b> 151 Nurses representing 7 hospital units</p>	<p>Nurses demonstrate apprehension on taking care of a person in end of life and his family, increasing the need to practice skills in this area.</p>

<p><b>Methodology:</b> Qualitative approach. [6]  <b>Levels of evidence:</b> IV  <b>Participants:</b> 104 patients who died after admission for stroke in the Health Sciences Center in Nova Scotia</p>	<p>Factors of conflict between the families and the health care team about palliative care were: provision of information, prognosis, the change to palliative care, comfort care, administration of therapy and cessation of nutrition/fluid.</p>
<p><b>Methodology:</b> Qualitative approach. Semi-structured interviews. Analysis of experiences of nurses in palliative care. [4]  <b>Levels of evidence:</b> IV  <b>Participants:</b> 33 nurses of oncology organized into nine discussion groups</p>	<p>Regarding palliative care there were considered: 5 nursing roles (teaching: preparation of client and family to make informed decisions on self-care and symptom control; care: support and provide physical, emotional and spiritual comfort; coordination: provide coordination of resources necessary for the development of common objectives; defense: assessing the needs and represent the patient and family in developing a treatment plan; mobilization: be aware and demonstrate dynamism in response to patient and family needs) and 7 professional attributes (clinical experience, honesty, family monitoring, perceptive attentiveness, availability, collaboration, deliberation).</p>
<p><b>Methodology:</b> Qualitative approach. Group discussion based on a structured guide with guiding topics. Follow-up workshops. [3]  <b>Levels of evidence:</b> IV  <b>Participants:</b> 23 Community Health Nurses</p>	<p>The advance care planning aims at establishing a therapeutic relationship between the patient in end of life and the professional, also involving the family. It promotes the patient to express the identification and meeting of their needs and treatment options. It's highlight the lack of resources to a genuine implementation of this plan, still it's referred the need for training and learning communication skills and suggested clinical supervision in order to strengthen confidence in the nurse's approach to patient's life and his family.</p>
<p><b>Methodology:</b> Qualitative approach. A descriptive study. Content Analysis. [5]  <b>Levels of evidence:</b> IV  <b>Participants:</b> 8 nurses working on an internment unit of a hospital specialized in palliative care in oncology in Rio de Janeiro.</p>	<p>The Nursing Care Systematization (NCS) can be understood as one of the great searches of nurses towards the qualification and humanization of care. The factors that hinder the implementation process of the NCS were: deficit of nursing human resources, lack of knowledge about the thematic and theoretical models for the systematization of care, need for commitment and adherence by all professionals involved in the process. For nurses, the oncologic patient have needs for biopsychosocial cares related mostly to the uncertainty of lifetime and the proximity of death. It is value home based care.</p>
<p><b>Methodology:</b> Qualitative approach. Application of questionnaires before and after guidelines - a comparative study. [2]  <b>Levels of evidence:</b> IV  <b>Participants:</b> Patients and caregivers from three oncology centers in NSW, Australia.</p>	<p>A systematic review of interventions to promote change in the provider's behavior, found that guidelines were more effective if active educational interventions and patient specific reminders were used. The use of workshops and seminars were used to assist in educating and training clinicians in the use of the Guidelines and NAT:PD-C, however research suggests that educational approaches using self-directed learning vary in effectiveness as health professionals vary in motivation to attend change and self-assess.</p>
<p><b>Methodology:</b> Qualitative approach. Semi-structured interview [1]  <b>Levels of evidence:</b> IV  <b>Participants:</b> 9 individuals with chronic disease (not yet at the end of life), averaged age of 86.5 years, residing in a rest home for a period not less than 6 months.</p>	<p>Individuals describe multidimensional needs: to be recognized as a person; choose and control their activities of daily living, such as food or health care (the biggest fear is to became totally dependent on professionals' care); to maintain the connection with the family is considered a source of strength; confidence and reason to live; stay socially active; have a religion, that is perceived as a source of confidence and support; physical comfort (pain and lost of physical mobility). The wish to die without pain as well as the existence of an environment where death is no longer considered a taboo subject was expressed.</p>

Table 1: Body of Analysis - Search on CINAHL, MEDLINE - Period 2000-2010.

<ul style="list-style-type: none"> <li>• <b>Ability to provide apacity for the provision of care to the person in end of life</b> <ul style="list-style-type: none"> <li>o Caring of the hygiene, nutrition, elimination, switching decubitus, use of equipments, symptoms control and the administration of medication.</li> </ul> </li> <li>• <b>Communication:</b> <ul style="list-style-type: none"> <li>o Understanding, negotiation and involvement in the decision making (sense of security in the multidisciplinary team).</li> </ul> </li> <li>• <b>Establishment of a trustful relationship:</b> <ul style="list-style-type: none"> <li>o Recognition and operationalization of the wishes;</li> <li>o Preparation for mourning;</li> <li>o Monitoring and involvement in the cares.</li> </ul> </li> <li>• <b>Needs:</b> <ul style="list-style-type: none"> <li>o Emotional;</li> <li>o Spiritual;</li> <li>o Resting;</li> <li>o Information.</li> </ul> </li> </ul>
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Table 2: Identified needs on caregivers of person in terminal stage - CINAHL and MEDLINE research (Period 2000-2010).

In order to implement effectively the strategies enounced above, nurses' emotional experiences during the care process of a patient in end-of-life and also supporting their relatives and family careers cannot be neglected. This is also considered an important dimension and its importance function as a link to the Palliative Care Team [15-19]. The nurses reveal themselves apprehensive by taking care of a people in end of life and their caregivers, and their concern vary according to the professional grade, gender, department and personal experience [2-7].

To supply quality on palliative care it is necessary for nurses to know the caregiver and the person in end of life (Table 2), establishing an early contact, ensuring a continuity of cares along the time and not being restricted to the physical aspects of cares [13,14].

## Conclusion and Implications for Professional Practice

Guide it by the question, "Which are the needs of end-of-life patients' caregivers, in terms of nursing care?". We conducted a critical analysis of all of the selected articles and we were able to develop a checklist of the needs of caregivers of a person in end of life, being the

majority of these corroborated by the authors that we have consulted for the elaboration of the validity of this systematic review, thus responding to this question.

Being the involvement of the caregiver an essential aspect in the care of the person in end of life, the caregiver should be capacitate to provide them, something that is not been verified, since the studies reviewed reported a deficit in this area.

Nursing interventions to the caregiver of the person in end of life are described in the table 3, in order to help the caregiver to deal with the situation and improve his quality of life.

With the elaboration of this systematic review we were able to identify the different needs of caregivers of the person in end of life, as well as identify key nursing interventions in order to give them an answer. The caregiver of the person in end of life has different needs, therefore, in his interventions, the nurse should be alert to recognize and satisfy this needs, based on the establishment of a trustful relationship, developing Nursing as a discipline and profession.

- Capacity [20].
- Knowledge and skills of the caregiver [1-6].
- Accompaniment by a nurse reference [13-17].
- Involvement in the cares [7,8].
- Emotional support [18, 19].
- Information and education [7,8].
- Spiritual support [17-20].
- Promotion of resting moments [9-11].

**Table 3:** Nursing interventions identified to the caregiver of people in end of life - CINAHL and MEDLINE Research (Period 2000-2010).

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