

# Factors influencing the experience of the terminal phase and the grieving process: the primary caregiver's perspective

Fatores que influenciam a vivência da fase terminal e de luto: perspectiva do cuidador principal

Factores que influyen en la experiencia del duelo y proceso terminal: Perspectiva del cuidador

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## Abstract

**Theoretical framework:** The experience of the terminal phase and death by patients and caregivers is influenced by multiple factors. This study aimed at understanding this experience from the primary caregiver's perspective.

**Objectives:** To describe the factors that, from the primary caregiver's perspective, influenced the experience of disease in the terminal phase and mourning for the death of a close person; To understand the influence of nurses' conduct on the experience of disease in the terminal phase and mourning for the death of a close person from the primary caregiver's perspective.

**Methodology:** Qualitative descriptive exploratory study.

**Results:** The following factors were valued: *To Assume the Caregiver's Role*, *To allow for the end-of-life/terminal phase to take place at home/near the family* and *Process of Care*. Regarding the nurses' conduct, the *knowledge, communication and relationship* established by nurses were also valued.

**Conclusion:** In addition to expanding the implementation of specific palliative care teams, the acquisition and development of basic skills in this area by most health care professionals is essential.

**Keywords:** terminally ill; grief; caregivers; nurse's role.

## Resumo

**Enquadramento:** Há múltiplos fatores que influenciam a vivência da fase terminal e morte por parte do doente e do cuidador. Este estudo visou compreender esta vivência, na perspetiva do cuidador principal.

**Objetivos:** Descrever os fatores que, na perspetiva do cuidador principal, influenciaram a vivência do processo de doença em fase terminal e de luto da morte da pessoa próxima; Conhecer a influência da conduta do enfermeiro, atribuída pelo cuidador principal, sobre a vivência do processo de doença em fase terminal e de luto da morte da pessoa próxima.

**Metodologia:** Qualitativa, tipo descritivo e exploratório.

**Resultados:** São valorizados o *Assumir Papel de Cuidador*, *Permitir que o fim de vida/fase terminal aconteça em casa/perto da família* e o *Processo de Cuidar*, assim como o *conhecimento, a comunicação e a relação* quanto à conduta do enfermeiro.

**Conclusão:** Além de equipas específicas, é indispensável a formação e competências básicas em cuidados paliativos, por parte da generalidade dos profissionais de saúde.

**Palavras-chave:** doente terminal; pesar(luto); cuidadores; papel do profissional de enfermagem.

## Resumen

**Marco contextual:** La experiencia de fase terminal y muerte por parte de los enfermos y de los que le acompañan es influenciada por varios factores. Este estudio tuvo como objetivo comprender esta experiencia, en la perspectiva del cuidador principal.

**Objetivos:** Describir los factores que, en la perspectiva del cuidador principal, han influido en la vivencia del proceso terminal y de duelo de la muerte de la persona próxima; Conocer la influencia de la conducta del enfermero, atribuida por el cuidador principal, sobre la vivencia del proceso terminal y de duelo de la muerte de la persona próxima.

**Metodología:** Cualitativa, descriptiva y exploratoria.

**Resultados:** Como factores que influyen en la experiencia de la fase terminal y del duelo habemos *asumir el rol de cuidador*, *Permitir que el final/ la etapa final de la vida / suceda en casa / cerca de la familia* y el *Proceso de Atención*. En cuanto a la conducta de las enfermeras se valoraron los conocimientos, la comunicación y la relación establecida por la enfermera.

**Conclusión:** Además de la extensión de la implementación de equipos específicos de cuidados paliativos, es esencial la formación y el desarrollo de habilidades básicas en esta área, en la generalidad de los profesionales de salud.

**Palabras clave:** enfermo terminal; pesar; cuidadores; rol de la enfermeira.

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## Introduction

Culture, history, the time in which one lives, and the way people live and understand life and religion contextualise and influence the way in which one experiences and accompanies a person's death.

The vision of death holds a common factor: Humankind cannot, nor want to, admit the *no-longer-being* of the person who dies; it is incomprehensible that the human consciousness will one day come to an end (Gadamer, 1997). In other words, death is both something that is always present throughout life and something that is denied in an attempt to minimise it in life.

The experience of the dying process by the person itself and the family depends on multiple factors, namely the resources, the context or if the responsibility of caring for the ill person was shared. The last stage of life, when conditioned by a long-term and incurable disease, is extremely complex and specific, since it involves the suffering of the person experiencing the process and those close to him/her. In line with this view, Barbosa (2006) mentions that long-term and irreversible diseases are associated with significant losses in patients, relatives and health care professionals, thus leading to sometimes complicated suffering and grieving processes. It is not possible to identify which process is more painful, whether caring for a loved one during the terminal phase of a disease or experiencing his/her loss. What we do know is that both will be part of a difficult period of life.

The grieving process is, therefore, quite complex and distinct in all situations, contexts and people.

The choice of the issue *Experience of disease in the terminal phase and grieving process: the primary caregiver's perspective* related to the concern to better understand that process so as to better adapt care/responses at the level of caring for the ill person, his/her caregiver and family, and accompany the grieving process. To this end, one of the study objectives was to describe the factors which, from the primary caregiver's perspective, influenced the experience of the process.

We believe this caregiver to be the person who most closely followed and experienced the whole process. Nurses who provide care to people in the terminal phase and their families, more specifically the primary caregivers at home, are often the professionals who spend more time with care receivers. Thus, a second

objective was set out: To analyse the influence of nurses' conduct on the experience of disease in the terminal phase and mourning for the death of a close person.

## Background

In the western culture, death gradually moved from being an experience lived within the family environment to be experienced in a hospital environment, with little family intervention.

"In truth, death remains our most unknown reality. We know when someone is dead but ignore what it means to die, as seen from the inside" (Nunes, 2009, p. 57). In fact, there is a lack of reflection about dying and death as a natural life process in our social context. Rather, it is understood as something to be repressed, and which is now a responsibility of health care professionals.

On the other hand, for a large number of health care professionals, dying is still not seen as a natural process, which ought to be properly accompanied at all stages. This idea is confirmed by Barbosa (2003, p. 8), who argues that "a large number of health care professionals is still little prepared to assist, understand, accompany and truly help a human being in the difficult moments prior to his/her death". But just as childbirth may be anticipated during pregnancy, the dying process may also be anticipated when people have a severe and incurable disease in an advanced stage. Either due to reaching a more advanced age, being worse for cases of disability and dependence, or due to the emergence of a severe and incurable disease or even due to the death of someone emotionally close or of similar age, death seems to have recognisable omens.

Advances in health sciences have determined an increase in longevity, with an increased number of people with greater frailty, chronic diseases and situations of disability, which, in turn, leads to an increased number of dependent people. Chronic diseases are now the leading cause of death. Chronic and severe diseases, also known as terminal illnesses, are associated with the awareness that the end of life may be near, nearer than ever imagined.

The concept of terminally ill patient is broad and involves various dimensions. The Spanish Society of Palliative Care (SECPAL, 2002) defines terminal

illness by pointing out the following characteristics: incurable, progressive and advanced disease; little or no possibility of response to active treatment; presence of numerous problems or intense, multiple, multifactorial and constantly changing symptoms; involvement of a great emotional impact on patients, families and health care professionals, resulting from the presence, explicit or not, of death; and limited life expectancy (less than six months).

Therefore, a terminal illness is not associated with a diagnosis, but rather with the negative impact of a given health problem on the lives of patients and families. Thus, the National Palliative Care Programme (2010) mentions that cancer, AIDS, advanced organ failure and some severe neurologic diseases are diseases that, among others, most affect people in need of palliative care. The terminal disease that involves intense suffering requires a specialised and specific health care approach. By observing the scarce and poor quality care provided to end-of-life patients, Cicely Saunders, a RN who later acquired medical training, wanted to draw attention to the need to offer rigorous, scientific and quality care - Palliative Care (Neto, 2006).

Palliative care is defined by the World Health Organization (WHO, 2002) as an approach that aims at improving the quality of life of patients and families facing problems associated with an incurable and/or severe illness, with limited prognosis through the prevention and relief of suffering by means of the early identification and impeccable treatment of not only physical problems, such as pain, but also psychosocial and spiritual problems. Palliative care includes four key instruments: symptomatic control, proper communication, support to the family, and teamwork. Each of these dimensions is equally important, thus requiring adequate training and practice by health care professionals in the four areas (Neto, 2006). It should be underlined that the transition between curative care and palliative care ought to be progressive, given that, during the whole process of disease, there will be moments of intense suffering to both patients and families, in which palliative care will be adequate (even when care is already being provided to fight the disease).

A mission of those who provide palliative care is to help find the *meaning of life*, engaging patients and families in all decisions relating to the health care to be provided and seeking to promote the therapeutic

alliance between the health care team, the patient and the family. This alliance is based on honesty between all participants, thus it is extremely important that the health care professionals involved have skills to deal with the communication challenges in palliative care. One of those challenges relies on the *conspiracy of silence*, which is based on the premise that hiding the truth from patients will avoid their unnecessary suffering (Astudillo et al. cited by Guarda, Galvão, & Gonçalves, 2006, p. 457).

The caring process within this area of care includes an effective response to the Grieving process. The way that the terminal stage is experienced and the history of both patients and grieving people are factors to be taken into account in order to anticipate and prevent complicated grieving processes. Various indicators of risk factors inherent to the grieving process are, therefore, presented. Twycross (2001) calls attention to the factors that might interfere with the way of experiencing grief: (a) The mode of death: unexpected or not; (b) The nature of the relationship: in a highly ambivalent relationship there is likely to be a more difficult bereavement, which is often manifested through guilt feelings; c) Perceived support: if the person feels supported by friends and family or isolated in his/her loss; d) Anticipatory grieving: if the family and the patient were able to share feelings and make plans for the future; e) Concurrent life events: level of stress that the key carer and family have to face, how many people are dependent on the key carer, and if the key carer has time and space to grieve; f) Previous losses: how has the person grieved in the past; g) Medical history: existence of physical or psychological conditions which may be exacerbated by the loss.

Based on the abovementioned points, it is clear that the complexity of these situations requires specific and specialised health care: Palliative Care. However, we know that palliative patients seek and receive care from various health care services. Authors such as Sapeta and Lopes (2007, p. 2) argue that “significant percentages of patients worldwide continue to use acute hospitals in this last phase of life, and subject themselves to that status”. The provision of health care to palliative patients is, thus, a responsibility of most health care professionals, including nurses who, due to their close contact with patients and their families, play an important role in the adaptation process.

In addition to identifying the factors which influence the experience of the terminal phase and grieving process, this study aimed at giving special attention to the influence of the nurses' conduct in this process.

### Research questions

The following research questions were formulated: From the primary caregiver's perspective, which factors influenced the experience of the terminal phase and mourning for the death of a close person? From the primary caregiver's perspective, what is the influence of the nurses' conduct on the experience of disease in the terminal phase and mourning for the death of a close person?

The following objectives were outlined: To describe the factors that, from the primary caregiver's perspective, influenced the experience of disease in the terminal phase and mourning for the death of a close person; and To understand, from the primary caregiver's perspective, the influence of nurses' conduct on the experience of disease in the terminal phase and mourning for the death of a close person.

## Methodology

Taking into account that we aimed at understanding the primary caregiver's perspective on the factors that influenced the terminal phase and mourning process for the death of a close person, a qualitative, descriptive and exploratory study was conducted.

The data collection tool used was the semi-structured interview.

Before interviewing the caregivers in this study, a different caregiver was interviewed who, although meeting the inclusion criteria, was not part of the study population.

The interview aimed at identifying potential limitations of the interview, testing the clarity and validity of the previously formulated questions, and developing interview technique skills. After this interview, the sixth question was included in the script, which was structured as follows:

1 – Could you, please, tell me when you first found out that your relative suffered from an incurable disease? When did you decide to take care of your relative?

2 – What helped you the most during the process of care? What was the most difficult part?

3 – Did you request any assistance from the Nursing team?

Did you and your relative receive visits from the nurse? How was the relationship between the nurse and the patient? And the nurse's relationship with you?

4 - As your relative's health status became worse, showing that the end of life was nearer, how did you react? Did you have to make any decision? Who provided you with support?

5 – Where did your relative die? Did you receive any support at that time? From whom?

6 – How have things been since the death of your relative?

7 - In relation to the nurse's work, what were the most positive aspects for you? And the most negative ones?

Given the nature of the study, its participants were chosen intentionally, based on meetings with the different visiting nurses, who worked at Health Care Centres integrated in the Local Health Unit of Baixo Alentejo (*Unidade Local de Saúde do Baixo Alentejo*). Nurses were asked to collaborate in the first contact with the caregivers under study. In the first meeting, the caregivers were informed of the study, its objectives and the intention to carry out the interview. Among the caregivers identified by nurses, two people refused to participate in the study. Thus, a total of seven caregivers participated in the study. The second contact with the caregivers who agreed to participate in the study was established by us, through a telephone call, to schedule the day, time and place of the interview. At this moment, data confidentiality and anonymity were also ensured.

The sample was composed of seven female participants, aged between 34 and 73 years. With respect to the level of education, the sample distribution varied between no level of education and Master's degree. As for the profession/professional situation, the typology included active and retired participants: Receptionist/active; Administrative/active; Rural worker/retired; Businesswoman/active; Teacher/retired; Hairdresser/active; and Journalist/active.

The sample size was defined by reaching data saturation.

The interviews were conducted between August 18 and September 15, 2009. Each interview lasted between 22 minutes and 92 minutes. They were carried out at the caregivers' homes, with the exception of two interviews which took place at the caregivers'

workplace. In all interviews, privacy was ensured so as to promote the interviewees' free expression. All interviews were also tape recorded following the consent of participants, who were informed that this procedure would facilitate data analysis. They were also informed that the data recorded would be used only for this purpose and that interviews would be erased afterwards. Upon the completion of all interviews, these were transcribed and their content was analysed using thematic categorisation, placing them in random order (E1, E2, E3, E4, E5, E6, E7), which was totally different from their chronological order and aimed at strengthening the interviewees' anonymity.

To start conducting the study, the summary of the dissertation proposal and respective written request to carry it out was submitted to the Head Nurse of the Local Health Unit of Baixo Alentejo. After its analysis by the Ethics Committee of the Unit, permission was obtained to conduct the study. The type of study that we aimed to carry out implied reflecting on experiences that could be associated with many feelings and emotions, thus the interviewee was ensured that his/her desire would be respected should he/she want to leave the interview. Since this topic is associated with an important emotional component that involves several ethical issues related to potential suffering and feelings of guilt, among other aspects,

an informed consent form was designed that aimed at clarifying the nature of the study, as well as the respect for the freedom to participate in it or not. This form was read prior to the interview, which started to be tape recorded after participants had given their informed consent to be interviewed. Due to the nature of the interview and the questions raised, the researcher needed to pay special attention to the caregivers given the emotional load associated with the topic. Possible limitations of the study resulted from the nature of the methodology used and the sample characteristics.

## Results

The categorisation allowed us to first build a grid of analysis for each interview and then a final grid, where all categories, subcategories, units of context and corresponding units of enumeration were grouped. From the analysis conducted, two categories with the respective subcategories were identified in our thematic area, which resulted in the grid shown in Table 1. Several units of context and associated units of registration were then identified in each subcategory. These units were intended to show and clarify our interpretation of the data.

Table 1  
Categories resulting from content analysis

Category	Subcategory	Units of Context	Units of Enumeration
Factors that influenced the experience of the disease process in the terminal phase and mourning for the death of a close person	To assume the Caregiver's Role	• To allow for the end of life/terminal phase to take place at home/near the family	17
		• Characteristics of the relationship with the patient	8
		• Family care at the end of life	6
		• The act of caring is inherent in being a family member	4
		Total	36
	Process of care	• Response from Health Care Professionals	32
		• Support from family/friends	20
		• To assist/being around those who suffer	17
		• Response from health care services	14
		• Proximity of death	9
		• Personal characteristics of the caregiver	7
		• Relationship with the patient/patient's attitude	7
		• Socio-professional responsibilities	7
		• Event of death	7
	• Knowing the family member's status – managing such knowledge	6	
Total	126		
Grieving process	• The process of caring	13	
	• Those who die remain here	5	
	• End of life as the end of suffering	3	
	• Support from family and friends	2	
	• Professional support	1	
	• Socio-professional responsibility (Daily life allows no time/opportunity to "mourn for the loss")	1	
Total	25		
Influence of nurses' conduct on the experience of disease in the terminal phase and mourning for the death of a close person	Relationship nurse/patient/caregiver	• Established communication/relationship	22
		• Availability	16
	Total	38	
Technical and instrumental skills	Technical knowledge/instrumental care	• Technical knowledge/instrumental care	10
		• Technical knowledge about process – Confidence in the provision of care	8
	Total	18	

The *Factors that influenced the experience of disease in the terminal phase and mourning for the death of a close person* category was composed of three subcategories. The sub category first to be identified was To Assume the Caregiver's Role. This subcategory concerned the specific moment (even if it could not be individualised and recognised) and the way the decision to assume that role was made. The individual and family adaptation to the crisis situation depends on the quality of family interactions and the meaning assigned by the family to the disease (Pereira & Lopes, cited by Araújo, Paúl, & Martins, 2008). It was concluded that the experience of the disease process of a close person is affected by the way how

the caregiver's role is assumed in terms of the reasons leading to that decision. In that regard, several reasons were identified based on the caregivers' answers.

The possibility of allowing for the end-of-life/terminal phase to take place at home/near the family was the most common reason given by caregivers. Thus, we concluded that it was important for caregivers to enable their loved ones to spend the last period of their lives at home, near those who were most close at heart.

In addition to this reason, other reasons were also identified that related to the caregiver's relationship with the patient, such as the characteristics of their relationship, their proximity and the respect for



what the person represented in the caregiver's life. Moreover, it was mentioned that family care at the end of life was the most appropriate care and that which offered what the patient needed.

The idea that the act of caring was inherent in being a family member was also presented, suggesting that taking care of the family member was not a decision, but rather an inevitable role assumed by those who were close to the patient (a relative). These findings were contradict with Karsch, cited by Cattani and Girardon-Perlini (2004), who argued that caregivers considered that their will and commitment resulted from their solidarity with the life partner, their desire to reciprocate the care received during childhood, their fear of institutionalisation, and the lack of other alternatives.

The second subcategory identified was the Process of care, which included the factors that were referred to as capable of influencing the performance of the caregiver's roles. The response from health care professionals was the most commonly mentioned factor, being referred to in both the positive and negative way. This was taking into account the adequacy or inadequacy felt by caregivers regarding the support provided by these professionals. Through the caregivers' reports, we may infer that they sometimes felt a lack of sensitivity and knowledge by health care professionals to deal with the situation.

Another factor seemed to be the support from family/friends. The informal support network was identified by the participants as a determinant of this process. The difficulty in assisting/being close to those who suffer and respond to the patient's needs in a situation of suffering was referred to as very demanding in terms of responsibility and the skills needed to ensure care. The awareness of the proximity of death may itself be a cause of great suffering and anguish, as Pacheco (2004, p. 136) mentioned: "The prospect of imminent death of a loved one normally causes much suffering to the family, which, in general, is still aggravated by a series of fears and feelings experienced throughout the process".

Another factor was the response from health care services, which almost always related to the inadequacy of response to situations of great suffering for both patients and families. On the one hand, we concluded that the health care services that were most accessible to people in these situations were often not the most appropriate ones and, on the other hand,

that there was no organisational preparation of these services to forward and adapt responses.

In this study, the proximity of death appeared as a factor which influenced the process of care. Being aware that death would result from the disease process was a hampering factor. A facilitating factor was the caregiver's characteristics, with a reference often being made to a *very powerful strength* that invaded the caregiver and allowed him/her to take care and continue to meet the needs.

The relationship with and the attitude of the patient during the whole process were also on the list of factors affecting the process of care. The references that lead us to infer this factor showed the difficulty in dealing with behaviours of anger and, in turn, the ease resulting from the patient's attitudes of acceptance.

Most of the caregivers interviewed had an opportunity to provide full-time care to a relative, some of them because they were retired, others because they were on sick leave, and others because they were self-employed and could be absent from work. Even so, the fact that they could not fulfill other socio-professional responsibilities was considered a hampering factor. In addition to job-related responsibilities, family responsibilities were also mentioned. These usually related to functions inherent to the role of mother, wife, grandmother or housewife, which were compromised as the role of caregiver was being secured.

The way how the patient dies, that is, if it is a peaceful moment, one that respects the wish of both the patient and family and is without intense suffering, facilitates the assumption of the caregiver's role. Hence, we concluded that, for the person close to the dying patient to go through the process of death, it is essential for him/her to prepare it beforehand.

Finally, managing the knowledge about the family member's status was considered to influence the performance of the caregiver's role. Through the caregivers' narratives, the difficulty inherent in holding knowledge about the situation and not being able to manage it with the patient became evident. Thus, the conspiracy of silence demands professional intervention, since it should be explained that the patient is in need of and seeks explanations for what is happening to him/her and what is going to happen in the near future (Faulkner cited by Guarda, Galvão, & Gonçalves, 2006). This intervention is of extreme importance to both the patient and the close person.

The third subcategory formed was the Grieving process, which included the factors that influenced how caregivers managed loss.

The process of care was the most commonly mentioned aspect. The way the caregiver accompanied and dealt with the patient until his/her death was a determinant of the grieving process, *i.e.* whenever a feeling of tranquillity/mission accomplished existed about the follow-up process of the person who died, grief seemed to be easier.

The idea that those who die remain here was expressed by caregivers as a way of living and adapting to loss. This thought was expressed when moments/situations of concern to maintain the habits/routines of the person who died were described, thus retaining his/her memory and presence, which was no longer a physical presence. Moreover, Pacheco (2004, p. 141) mentioned that "The nature of the relationship with the deceased person has great importance in how grief is experienced."

The end of life as the end of suffering was also presented as a facilitator to accept death and loss. Whenever the caregiver felt that the disease process was causing great suffering for the relative, death appeared as a form of relief. This may be a facilitating factor of accepting the end of life.

The support from family and friends, as well as the professional support, were less frequently mentioned by caregivers as factors influencing the experience of grief. This support was mentioned as important: the lack of it was a hampering factor, while its existence was a facilitating factor. One of the caregivers also pointed out the lack of personal time in the moments that followed the death of the relative, mentioning that daily life did not allow time/opportunity to mourn for the loss of loved ones.

*The Influence of nurses' conduct on the experience of disease in the terminal phase and mourning for the death of a close person* category was composed of two subcategories. The first was the Nurse/patient/caregiver relationship, which included the aspect most valued by caregivers, *i.e.* the established communication/relationship. This was not in line with the expectations related to the functional contents of Nursing and the relational basis in which the profession is developed. According to Nunes (2008, p. 44), "the care process is an interpersonal relationship, in which the nurse's competence is based on his/her commitment to care for the other and his/her

intention to assert the other as a person, thus setting up a protective care". To a large extent, the reference to communication and its suitability during the process was associated with the importance assigned to knowledge and the transmission of information about what was going on and the disease process itself. The relationship and communication established by nurses with both the patient and family were referred to as facilitators of the experience under study. The fact that the nurse showed his/her availability to be present, provide a response and answer the phone was mentioned as important to the experience of the terminal phase for both the caregiver and the patient. The Technical and instrumental skills constituted the second subcategory, which concerned the *technical knowledge and instrumental care*. These were valued by the caregivers and concerned the techniques and care which could only be developed by nurses. The recognition of the nurses' know-how by the caregivers was in line with one of our expectations. However, it should be highlighted that their know-how was less frequently mentioned than the relationship and communication established by these professionals. Within this subcategory, the technical knowledge on the process - Confidence in the provision of care should also be highlighted. The caregivers appreciated the fact that the nurse was familiar with the situation and a professional who could be trusted as a resource and relied on in case of doubts about the situation. They considered that nurses had given adequate responses, be it regarding the doubts about the situation itself or regarding the direct care provided to the patient.

## Conclusion

This study allowed us to understand, from the caregiver's perspective, what influenced the experience of the terminal phase and mourning process and the extent to which nurses' conduct influenced such experience. Based on the results found, it is now possible to reflect on the practice and the most appropriate changes and/or investments to be made in the area of palliative care and end-of-life care, in general.

Although these are specific situations, with specific needs in terms of responses from health care services, we know and confirmed with this study that



terminally ill patients and their families use different health care services at the home care, hospitalisation and emergency levels. Regarding the aspects which influenced the experience of the terminal phase and mourning process, the factors pointed out by caregivers were divided into three subcategories. The first subcategory, *To Assume the Caregiver's Role*, included the motivations for caring, the most valued aspect being *To allow for the end-of-life/terminal phase to take place at home/near the family*. In relation to the subcategory *Process of care*, the most commonly mentioned aspects were *response from health care professionals* and *support from family/friends*. Finally, in the subcategory *Grieving Process*, the most common factor mentioned by the caregivers as having an influence on this process was the *process of care*.

We would also like to make a few remarks about the findings regarding the caregivers' perspective on the response from health care services. The caregivers most often expressed the inadequacy of response at the emergency level and poor response at the hospitalisation level. We believe that a strong investment in palliative care is needed, especially in home care, and that there is the need for care to be provided by competent professionals in the field of palliative care, who, in addition to providing direct care, may also assist in decision-making processes. The patient's transition from home to the hospital and back home will have to be monitored by professionals who are familiar with the process. The referral and welcoming of terminally ill patients and their families should always be performed by professionals that they know and who can provide appropriate responses, thus avoiding the use of the emergency service. This service is able to give an immediate solution to acute situations that jeopardise people's health and life, but is not prepared for crisis situations often related to such specific needs of the chronic and progressive disease process. Even so, we know that the use of these services will always occur, since there may be situations of lack of symptomatic control that may not be solved at home in the short term. Thus, it seems essential to us that the response provided to terminally ill patients should be more appropriate. The strengthening of community teams in the area of palliative care is an obvious need, as is the basic training of professionals working in different health care services. We believe that the awareness of this

reality by health care professionals may involve understanding the implications of their practices on the lives of those who are suffering. With regard specifically to nurses' conduct, this study calls our attention to the importance assigned by caregivers to the knowledge, communication and relationship established by nurses, which are considered to be more important than instrumental care. The caregivers mentioned the need to be prepared for the reality of the situation, valuing the information and strengthening of realistic hope provided by nurses. This finding makes us reflect on the need for nurses to be prepared to communicate and establish a relationship with patients, families/carers, which are so important in the experience of the terminal phase and mourning process.

In short, this study allowed us to confirm the need to further expand the implementation of palliative care teams at the community and hospitalisation levels. It also confirmed that awareness is needed from all health care professionals about the importance of acquiring skills that allow for, on the one hand, the practice of palliative actions and, on the other hand, the adequate referral of patients and families to palliative care teams.

## References

- Araújo, I. M., Paúl, C., & Martins, M. M. (2008). Cuidar das famílias com um idoso dependente por AVC: Do hospital à comunidade: Um desafio. *Referência*, 2(7), 43-53.
- Barbosa, A. (2003). Pensar a morte nos cuidados de saúde. *Análise Social*, 38(166), 35-49.
- Barbosa, A. (2006). Luto. In A. Barbosa & I. G. Neto, *Manual de cuidados paliativos* (pp. 485-510). Lisboa, Portugal: Faculdade de Medicina de Lisboa.
- Cattani, R. B., & Girardon-Perlini, N. M. O. (2004). Cuidar do idoso doente no domicílio na voz de cuidadores familiares. *Revista Electrónica de Enfermagem*, 6(2). Retrieved from www.fen.ufg.br.
- Direção Geral da Saúde. (2010). *Programa Nacional de Cuidados Paliativos*. Lisboa, Portugal: DGS.
- Gadamer, H.G. (1997). *O mistério da saúde: O cuidado da saúde a arte da medicina*. Lisboa, Portugal: Edições 70.
- Guarda, H., Galvão, C., & Gonçalves, M. J. (2006). In A. Barbosa & I. G. Neto, *Manual dos Cuidados Paliativos* (pp.17-49). Lisboa, Portugal: Faculdade de Medicina de Lisboa.

- Sociedad Española de Cuidados Paliativos. (2002). *Guía de cuidados paliativos*. Retrieved from <http://www.secpal.com/guiacp>.
- Neto, I. G. (2006). Princípios e filosofia dos cuidados paliativos. In A. Barbosa & I. G. Neto, *Manual de Cuidados Paliativos* (pp. 17-49). Lisboa, Portugal: Faculdade de Medicina de Lisboa.
- Nunes, L. (2008). Fundamentos éticos da deontologia profissional. *Ordem dos Enfermeiros*, (31), 33-45
- Nunes, L. (2009). *Ética: raízes e florescências em todos os caminhos*. Loures, Portugal: Lusociência.
- World Health Organization. (2002). *Definition of Palliative Care*. Retrieved from <http://www.who.int/cancer/palliative/definition/en/>
- Twycross, R. (2001). *Cuidados Paliativos* (1ª ed.). Lisboa, Portugal: Climepsi Editores.