

# Caring for a Person with Advanced Disease in the Community: Phenomenological Study

Cuidar da Pessoa com Doença Avançada na Comunidade: Estudo Fenomenológico  
Cuidar de una Persona con Enfermedad Avanzada en la Comunidad: Estudio Fenomenológico

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## Abstract

**Background:** Demographic aging and the increased prevalence of chronic, progressive and disabling diseases explain the importance of the caregiver in the community.

**Objectives:** To describe and analyze the meaning of the lived experience of the caregivers of the person with advanced disease in the community.

**Methodology:** Phenomenological study, using Giorgi's method and semi-structured interviews. Eight caregivers living in the northern region of Portugal were interviewed from January to May 2013.

**Results:** Eight themes were identified: Being a caregiver of a person with advanced disease in the community; communication; respect for human dignity; complicating factors and facilitating factors; coping mechanisms; positive and negative feelings.

**Conclusion:** The caregivers of people with advanced disease in the community experience diverse situations with a positive or negative impact on their life and health. Although there are difficulties and negative feelings, such as fear and sadness, factors that facilitate care and positive feelings, such as satisfaction and hope, are also present in the caregivers' interviews. We suggest a reflection on care organization and on the healthcare professional's education and performance in this context.

**Keywords:** community; palliative care; caregivers

## Resumo

**Enquadramento:** O envelhecimento demográfico e o aumento da prevalência de doenças crónicas, progressivas e incapacitantes fundamentam a importância do cuidador na comunidade.

**Objetivos:** Descrever e analisar o significado da experiência vivida pelos cuidadores da pessoa com doença avançada na comunidade.

**Metodologia:** Estudo fenomenológico, segundo método de Giorgi, recorrendo a entrevista semiestruturada. Entrevistaram-se 8 cuidadores que residem na região interior do norte de Portugal, de janeiro a maio de 2013.

**Resultados:** Identificaram-se 8 temas: Ser cuidador de pessoa com doença avançada em contexto comunitário; comunicação; respeito pela dignidade humana; fatores dificultadores e fatores facilitadores; mecanismos de *coping*; sentimentos positivos e negativos.

**Conclusão:** Os cuidadores das pessoas com doença avançada na comunidade vivenciam experiências diversas com repercussões positivas e negativas na sua vida e saúde. Embora surjam dificuldades e sentimentos negativos, como medo e tristeza, os fatores facilitadores do cuidado e sentimentos positivos, como satisfação e esperança, são também perceptíveis nos discursos dos cuidadores. Sugere-se uma reflexão acerca da organização dos cuidados, e da formação e atuação dos profissionais de saúde neste contexto.

**Palavras-chave:** comunidade; cuidados paliativos; cuidadores

## Resumen

**Marco contextual:** El envejecimiento demográfico y el aumento de la prevalencia de las enfermedades crónicas progresivas e incapacitantes explican la importancia del cuidador en la comunidad.

**Objetivos:** Describir y analizar el significado de la experiencia vivida por los cuidadores de la persona con enfermedad avanzada en la comunidad.

**Metodología:** Estudio fenomenológico, en el cual se utilizó el método de Giorgi y la entrevista semiestructurada. Se entrevistó a 8 cuidadores que residen en la región interior del norte de Portugal, de enero a mayo de 2013.

**Resultados:** Se identificaron 8 temas: Ser cuidador de la persona con una enfermedad avanzada en un contexto comunitario; comunicación; respeto por la dignidad humana; factores dificultadores y factores facilitadores; mecanismos de *coping*; sentimientos positivos y negativos.

**Conclusión:** Los cuidadores de las personas con enfermedad avanzada en la comunidad viven experiencias diversas con repercusiones positivas y negativas en su vida y salud. Aunque surjan dificultades y sentimientos negativos, como el miedo y la tristeza, surgen también en el discurso de los cuidadores factores que facilitan el cuidado y los sentimientos positivos, como la satisfacción y la esperanza. Se sugiere hacer una reflexión sobre la organización de los cuidados, la formación y la actuación de los profesionales de la salud en este contexto.

**Palabras clave:** comunidad; cuidados paliativos; cuidadores

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## Introduction

The increase in the average life expectancy and the prevalence of chronic diseases is an important health issue, leading sometimes to situations of dependency and disability. There are new specific health needs for which governments around the world are not yet able to provide a response (Marques, Teixeira, & Souza, 2012). In recent decades, palliative care has emerged as an alternative response to the most complex health situations. The needs for this type of care are expected to increase (Worldwide Palliative Care Alliance, 2014). Given the technological advances and improved health care, care which was only provided in hospital settings can now be provided at home. This allows keeping people with advanced chronic diseases at home and, simultaneously, reducing the social and economic costs inherent to the hospitalization process (Sequeira, 2013).

In this context, the caregiver emerges as someone able to meet the individual needs of the person with advanced disease, integrated in the family dynamics, providing care at home. This issue was the starting point for this study. Therefore, the main objective was to identify the meaning of the lived experience of the caregiver of the person with advanced disease in the community.

## Background

### Caring for the Person with Advanced Disease in the Community

The caregiver is a family member, friend or other person who has a significant non-professional or unpaid relationship with and provides individualized care to another person (Payne, 2010). The role played by the caregivers in the community at the end of life is essential, and it is associated with high social, economic and health costs. End-of-life care is something complex that involves new tasks and responsibilities for which the family usually feels unprepared (Funk et al., 2010).

At the international level, a change from a reactive attitude to a preventive attitude in healthcare provision is supported, moving the attention from hospital-centered care to community care, considering that this is the only way to obtain real health gains (Currow et al., 2011).

### Palliative Care as a Response

The community palliative approach to the person with advanced chronic disease is based on scientific principles, with clear objectives related to the reduction of suffering and the promotion of quality of life. Palliative care improves the quality of life of patients and their families who are facing problems associated with a potentially life-threatening disease, through the prevention and relief of suffering by means of early identification and appropriate assessment and treatment of pain and other physical, psychological and spiritual problems (Worldwide Palliative Care Alliance, 2014).

In palliative care, the family plays a decisive role in supporting the person with advanced disease and also suffers the impact of the disease, thus it should both provide and receive care (Hudson, Thomas, Quinn, Cockayne, & Braithwaite, 2009).

## Research Questions

In order to better express what we expect to find, we formulated the following key research question: What is the meaning of the lived experience of the caregiver of the person with advanced disease in the community?. We defined the following specific objectives: To analyze the lived experiences of the caregivers of the person with advanced disease in the community; To understand the meaning assigned by the caregivers to the care provided to the person with advanced disease in the community; To analyze the difficulties experienced by the caregivers of the person with advanced disease in the community; To explore both positive and negative experiences and feelings experienced by the caregivers of the person with advanced disease in the community.

## Methodology

Based on the participants' interviews to understand the perceptions and experiences of the caregivers of the person with advanced disease in the community, we used a phenomenological approach. Phenomenology aims to describe a phenomenon through the meanings that people attach to the situations, using the analysis of their lived experiences (Streubert & Carpenter, 2002).

The methodological guidance used was the phenomenological analysis proposed by Giorgi in 1985 (cited in Streubert & Carpenter, 2002), whose objective is the search for the meaning of human action through comprehension. The steps proposed by Giorgi are as follows:

1. Read an entire description of the experience to gain an impression of the whole;
2. Re-read the description;
3. Identify the transition units of the experience;
4. Clarify and elaborate the meaning by relating the constituents with each other and with the whole;
5. Reflect on the constituents using the concrete language of the participant;
6. Transform the concrete language into scientific language or concepts;
7. Integrate and synthesize the insights into a descriptive structure of the meaning of the experience (cited in Streubert & Carpenter, 2002, p. 56)

To this end, we used semi-structured interviews, given the abstract nature of the questions raised and for being appropriate to the goals of this study. All interviews were recorded and transcribed, being subsequently destroyed.

### **Type of Study**

This is an exploratory, descriptive study with a qualitative research approach. According to Madureira (2012), qualitative research addresses meanings, reasons, aspirations, beliefs, values and attitudes. The purpose of this study is to describe and analyze the meaning of the lived experience of the caregivers of the person with advanced disease in the community.

### **Participants**

Eight caregivers of patients with advanced disease who lived in the area of influence of a Healthcare Cluster (ACeS) of the northern region of Portugal participated in this study. To facilitate the process of participant selection, we requested the collaboration of liaison persons from the functional units of the ACeS. We considered an advanced disease to be any chronic disease with significant and disabling progression, with the association of symptoms potentially leading to physical, psychological, social or spiritual suffering, regardless of the expected survival rate. The following inclusion criteria were defined: being Portuguese; and being the main caregiver of person with advanced disease in the community for 6 months or more. The

exclusion criteria were being under 18 years of age and being cognitively impaired.

### **Formal and Ethical Procedures**

The research project was assessed by the Ethics Committee of the Health Sciences Research Unit of the Nursing School of Coimbra, which issued a favorable opinion (P111-10/2012). Authorization was obtained from the Executive Director of the ACeS for the implementation of the study. The informed consent was obtained from all the participants, who were given the necessary information and ensured of the study's confidentiality and anonymity.

### **Data Collection Instrument**

The instrument used for data collection was composed of two parts: A sociodemographic questionnaire for participant characterization and an interview script with two open-ended questions for caregivers to report on their experience. The interviews were conducted from January to May 2013 and had a mean duration of 41.6 minutes.

## **Results and Discussion**

All interviewees are female and Catholic. The mean age is 57.3 years, with six of the caregivers being 60 years or above. Half of the interviewees are daughters of the person being cared for (50.0%), seven are married or cohabiting (87.5%), most of them have a low level of education (75.0% only attended primary education) and are homemakers (75.0%). The interviewees have been providing care for an average of 7.7 years.

The caregiver profile obtained in this study is similar to that reported in other studies (Cohen, Colantonio, & Vernich, 2002; Proot et al., 2003; Sequeira, 2013), although there are slight differences in relation to the level of education and the degree of kinship. Even so, it corroborates that the responsibility for providing care is usually assumed by the closest relatives or a significant person.

The mean age is highly relevant here, as health problems, such as physical degradation and less strength and agility, arise from the aging process of the caregiver himself/herself (Sequeira, 2013). We believe that the duration of care provision is also very important, since caregivers who have been providing care for a longer period of time are at a greater risk for

physical, social, and emotional problems (Proot et al., 2003; Sequeira, 2013).

In relation to the profile of the people with advanced disease, the mean age is 75.0 years, most are females (66.7%) and 44.4% are widows. The most common diagnosis is cancer (44.4%).

Figure 1 shows the structure of the phenomenon, as it was understood. Eight major themes were identified in the findings: Being a caregiver of a person with advanced disease in the community; communication; respect for human dignity; complicating factors and facilitating factors; coping mechanisms; positive and negative feelings.

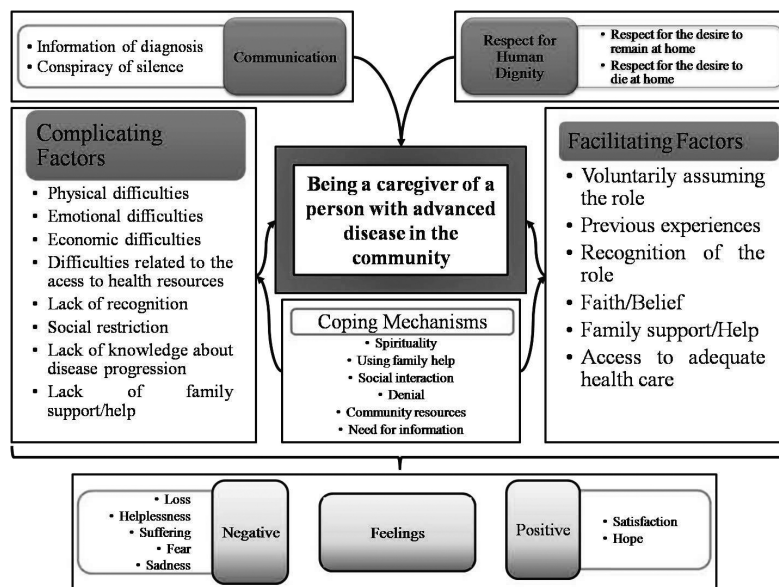


Figure 1. Empirical Structure for Phenomenon Analysis.

## Being a Caregiver of a Person with Advanced Disease in the Community

For a better understanding of the lived experiences of caregivers in the community, it is important to identify their reasons for assuming this role and understand the meaning attached to *being a caregiver* in this specific context.

The central theme of this research is *Being a caregiver of a person with advanced disease in the community* and is influenced by the remaining seven themes.

### Communication

Communication is an experience which directly influences the condition of caregiver. In this category, two subthemes emerged: the information of the diagnosis and the conspiracy of silence.

All participants believe that the information of the diagnosis obtained from the health team was sufficient, although indications of conspiracy of silence are common in the interviews. The information of the diagnosis determines the attitude toward the disease

itself, decision-making and the subsequent action of the patient and the family, which influences the quality of life. The information increases the ability to accept the disease and generate feelings of security and control of the situation (Surribas & Fontanella, 2006). "He told my husband straight up ... The doctor told us just like that ... In hospital [X], it's different, they speak in a different way, even to him". E1 (January, 2013).

There are also cases where the family believes that the patient is unable to deal with the truth. Surribas and Fontanella (2006) consider that some family members select the information that they pass on to the patient to spare him/her of suffering, seeking to relieve his/her pain, anxiety and anguish:

No, my father doesn't know. He knows he has a tumor ... I'll never tell him ... because my father is very strong and that's what has been helping him. If he loses that hope, he will pass away sooner. I can't. E3 (February, 2013)

## Respect for Human Dignity

The respect for human dignity is associated with the following two subthemes: respect for the desire to remain at home and respect for the desire to die at home. "As long as I'm capable, she's not going anywhere else ... I'm getting by as I can". E8 (May, 2013).

The intention to respect the desire to remain at home is a common aspect to five caregivers. This notion is recurring in the literature. The people being cared for usually mention that they would like to be cared for at home, next to their family. The importance of remaining within the family context seems to be essential for chronic patients at an advanced stage (Benzein, Norberg, & Saveman, 2001).

The respect for the patient's desire to die at home is referred to by four caregivers. "I told [the doctor] that I wanted to take her home and [the doctor] asked me why, I told [the doctor] that it was because I wanted her to die at home, that I didn't want her to stay at the hospital". E7 (April, 2013). This choice also seems to be a desire of the caregiver. This aspect is also mentioned in some international studies (Cohen et al., 2002; Proot et al., 2003). In this study, all of the respondents are catholic, being that faith and belief emerge in this study as a substantial part of the experience that could explain this choice. In addition, the study was developed in a rural area, where the moral and social values still seem to impose a certain ethical hierarchy regarding the provision of care to family members and older people.

## Complicating Factors

The following subthemes stood out as complicating factors: physical difficulties; emotional difficulties; economic difficulties; difficulties related to the access to health resources; lack of recognition; social restriction; and lack of knowledge about disease progression.

The difficulties experienced by the caregivers and the obstacles to care provision are mentioned in several national and international studies (Bocchi, 2004; Pavarini et al., 2008; Cruz, Loureiro, Silva, & Fernandes, 2010; Cerqueira, 2012; Sequeira, 2013). In 2003, Proot et al. conducted a study about the factors that contributed to the vulnerability of caregivers of palliative care patients at home, concluding that the difficulties experienced by the caregivers increased their vulnerability.

The physical difficulties are common to all interviews. The caregivers mentioned feeling, sometimes, unable to perform tasks requiring physical effort: "I can't wash him ... not by myself ... It's very hard for me." E1 (January, 2013). Pavarini et al. (2008) refer that the physical and instrumental functional limitations of the dependent person represent an overburden for caregivers.

The acceptance of the health status of the person with advanced disease emerged as another difficulty: "Very skinny arms. I never thought I would see my father like this ... But the hardest thing is dealing with his suffering." E3 (February, 2013).

The economic difficulties are related with the health costs inherent to the needs of the person with advanced disease, which are associated with the caregiver's lack of remuneration. These reasons can be found in other studies (Cruz et al., 2010).

Her pension is very small and I can't work because I'm taking care of her ... I want her to have everything she needs ... We have some difficulties but I can only spend what I got." E4 (March, 2013)

Some caregivers reported being satisfied with the access to health care and considered them to be adequate. Paradoxically, the opposite feeling is also frequent in interviews E1, E2 and E3.

Based on the interviews, we can infer that the difficulty in the access to health resources hinders the provision of care to the person with advanced disease. The lack of information on disease progression seems to prevent the caregiver from clarifying his/her doubts, fears and concerns and, consequently, preparing for the losses and bereavement of daily life (Cerqueira, 2012).

I would like them to explain things ... a bit of time, to talk to him ... sometimes I'm the one who starts talking to them [nurses], perhaps because we, as caregivers, feel the need to receive a bit of attention, instead of doing things quickly and going away. E3 (February, 2013)

The lack of recognition of the role played by the caregiver is another complicating factor. In E2, the lack of recognition by the person being cared for is a key aspect which hinders the act of caring. E3 and E7 demonstrated the need for recognition by the remaining family members. "But at the beginning, my husband complained that I was always with my father. I came to a point where I thought I was going to crack,



because it's not easy". E3 (February, 2013).

Being responsible for the provision of care to the person with advanced disease required a great deal of dedication and availability. Caregivers experience changes in their lifestyles that can create discontent in their social life and may lead to isolation (Bocchi, 2004).

I spent my life here ... I never go out ... I've never worked, I was always at home ... I never went to a party, I've never gone anywhere, I was always here. Trapped ... I wish ... I was not alone. E2 (February, 2013)

Social restriction is referred to by five caregivers as a complicating factor in the performance of the role of caregiver. This restriction refers to the social environment of the patients and the family itself. This feeling also emerges in other studies (Cruz et al., 2010).

### Facilitating factors

The following themes emerge as facilitating factors: voluntarily assuming the role; previous experiences; faith/belief; recognition of the role; family support/help; and access to adequate health care.

There is less evidence about the facilitating factors of the performance of the caregiver's role than about the complicating factors. Proot et al. (2003) refer that an adequate supervision from a health team and the sense of satisfaction are factors that reduce the vulnerability of the caregivers of palliative care patients at home, thus facilitating the provision of care.

The participants present different reasons for assuming the role of caregiver. The spouses mention an obligation to provide care. The interviews seem to indicate that this fact may have a marked moral, cultural and social basis, perhaps associated with family and religious traditions. The children pointed to their life situation and their role within the family as justification: Because they already lived with the person before (E2 and E4), because they were single (E2) or unemployed at the time (E3 and E7). "I'm glad to care for him, for God sake, who would do it like I do? [smile] that's it, nobody". E1 (January, 2013). Therefore, the person who assumed the role of caregiver was the one who was more available and capable of doing it within the family system (Sequeira, 2013).

The previous experiences arise as another facilitating factor in three of the eight interviews. "My life started

when I was 13, caring for my mother, then for my father, ... my mother-in-law, ... my husband's grandmother ... and then my husband". E4 (March, 2014). This factor is also mentioned by Stajduhar, Funk, and Outcalt (2013) as one of the primary descriptors of the caregiver's learning process.

Faith and belief are another facilitating factor, which allows them to accept reality better and endure the adversities along the way, fostering their values and decision making. "Faith is very important, I hold on to it a lot ... It really helps me". E8 (May, 2013). Believing in a higher power and developing spirituality seems to be a source of emotional support for the caregivers in the most difficult moments, helping them to cope with the difficulties and the suffering (Oliveira et al., 2012).

Other facilitating factors found in the interviews are the family support/help and the recognition of the role.

My sister ... she helped me a lot and taught me how to do it. And today she says that I'm even more experienced than her, that I was a positive surprise and today ... I am truly capable of doing everything, without any fears. E7 (April, 2013)

The family seems to be a source of help and support that mitigates the caregiver's sense of overburden and encourages the care experience (Proot et al., 2003). The recognition of the role played by the caregiver is a positive aspect of the care process that can contribute to the caregiver's sense of satisfaction and well-being (Sequeira, 2013).

With regard to the access to adequate health care, the relationships with the professionals proved to be positive, increasing the caregiver's well-being and confidence. "Whenever I needed anything ... they were always there ...". E7 (April, 2013).

When questioned directly about the health care available, the caregivers seemed to be satisfied with the care received. However, throughout the interviews, it is possible to realize that the caregiver's expectations in this context are low, and gaps and difficulties were found that seem to be related to deficits of access to adequate health care. The access to adequate health care is mentioned in the literature as an important feature for the performance of the role of caregiver. Proot et al. (2003) concluded that the health care available to the caregivers of palliative care patients at home were insufficient, thus contributing to their situation of vulnerability. Other

studies also emphasize the need for an appropriate intervention from the health professionals since it can have a positive impact in this context (Cohen et al., 2002; Sequeira, 2013).

### **Coping Mechanisms**

The coping mechanisms mentioned by the caregivers are spirituality; use of family help; social interaction; community resources; need for information; and denial. The reference to community resources is scarce in the interviews. However, they seem to be important for the caregivers, mainly in minimizing physical difficulties. Proot et al. (2003) argue that caring for someone with an advanced disease at home requires a constant balance between the sense of overburden and the coping strategies.

Using the help of the family was a strategy of four caregivers. This is a common coping mechanism in studies related to this theme (Proot et al., 2003; Cruz et al., 2010; Sequeira, 2013). "But when I see that she's down, I ask my sister for help". E8 (May, 2013). Through interviews E5 and E7, we can infer that social interaction is a coping mechanism that contributes to reduce the caregiver's burden. This fact seems to be related with social restriction, since social interaction minimizes this complicating factor, thus decreasing the negative repercussions associated with caring from the caregivers' perspective. These aspects are also referred to in the study of Sequeira (2013). "Sometimes I go to my neighbor's house, we are close friends ... I go there to talk a little bit with her". E5 (March, 2013).

Spirituality emerges associated with matters of faith and belief, helping the caregivers to understand the meaning of life. Spirituality seems to be experienced as a coping mechanism that minimizes the challenges experienced and decreases tensions, helping the caregivers in the search for a meaning in life. "God may have closed a door on me, but he opened so many windows. I feel grateful in every way." E7 (April, 2013).

The empowerment of caregivers by satisfying their information needs seems to be an important factor, allowing them to meet the real needs of the person with advanced disease. The caregiver needs support and understanding in relation to several topics, especially as the time of death draws nearer (Madureira, 2012). "I think that ... Maybe I shouldn't know so much, but it's also good, because I know what

to expect ... I need this knowledge ... to prepare me and to help him the best I can". E3 (February, 2013).

### **Negative Feelings**

The negative feelings expressed by the caregivers were loss, helplessness, suffering, fear, and sadness. Due to their demanding role, the caregivers mentioned various losses: of family and social ties; job opportunities; and the image that they had from the person before disease progression. The negative repercussions of caring have been studied both nationally and internationally (Proot et al., 2003; Cerqueira, 2012; Sequeira, 2013). "This week I suspended my job and my consultations ... I believe that I cannot push my work aside because ... If I say no, they won't call me again". E3 (February, 2013).

The perceived or real loss of the loved one, the uncertainty of the future and the concern associated with a potential inability to care for the person are experienced through fear and sadness. "I've cared for her very well until now, she is confined to bed now, it's more ... It's hard seeing her like that. It's hard wanting to do things and sometimes just not being able to ... that's it". E2 (February, 2013).

The feeling of helplessness is experienced through the dissatisfaction and frustration given the inability to perform some tasks and alleviate the patient's suffering.

The negative feelings associated with caring put the caregiver in a situation of greater vulnerability. On the other hand, aspects such as the sense of satisfaction with caring and appropriate monitoring by the health teams contribute to reduce this vulnerability (Proot et al., 2003).

### **Positive Feelings**

Participants see caring as an enriching task. Hope is experienced as something pleasant that contributes to empower the caregiver. The caregivers believe that caring for someone can provide feelings of valorization and personal growth, satisfaction with the fulfilment of the role, and social recovery. Souza et al. (2005) also found that 30% of the interviewees mentioned enjoying and feeling pleasure by taking care of their patients.

If I can only give this, I give much affection. But I really don't care ... I feel that I have to do this because he's my father. Because of the love we have and because I can't think of delegating this

to another person. Despite everything being so difficult, it doesn't matter. E3 (February, 2013).

Cohen et al. (2002) performed a study with 289 caregivers, concluding that 70% recognizes at least one positive aspect associated with caring. The following positive aspects were highlighted: sense of companionship; sense of reward and meaning of life; satisfaction and sense of providing quality of life.

As the main limitation of this study, it is important to mention that the size of the sample and its homogeneity may have hindered the expression of all perceptions and strategies used by the caregivers. Despite this, we believe that this study allows inferring and reflecting on what it means to be a caregiver of the person with advanced disease in the community.

## Conclusion

Caring for people with advanced disease in the community poses many challenges to the caregiver. They are faced with difficulties related to their characteristics and to those of the person being cared for. This study provided a reflection about the lived experience of the caregivers, which is sometimes not at the center of the discussions by families, health professionals and the society in general.

The caring process in this context has repercussions on the life of the caregivers in the following dimensions: physical, economic, social, psychological, and emotional. These caregivers have shown that they assume responsibilities beyond their limits, which is why they should be supported, valued and recognized for their role.

Although the need for palliative home care teams is often discussed, the information that the general population has about these teams is still scarce, reflecting a low expectation toward health care in the context of advanced chronic diseases.

We believe that it is essential to reflect on the organization of health care in Portugal, and that there must be a greater investment in the community, particularly in palliative care. The promotion of social and health policies, aimed at encouraging the maintenance of family solidarity between generations, with the participation of all family members is also necessary.

The adoption of strategies by the health professionals could contribute to improve the provision of health

care to this population. The training on palliative care and the implementation of specific interventions with a view to decreasing the overburden and promoting the well-being of the caregiver may be viable strategies. We also believe that the genesis and orientation of health care in the community should be restructured. It is expected to be founded in fundamental values of respect for human dignity, with community palliative care teams emerging as a viable alternative.

We suggest that this study should be replicated in other parts of the country, which could contribute to a better and more comprehensive understanding of the experiences of these caregivers.

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