http://dx.doi.org/10.1590/1809-98232016019.150178

Palliative Care for Institutionalized Elderly Persons: Experience of Caregivers

Matilde Sampaio Carvalho[1]
José Carlos Amado Martins[2]

Abstract

The number of elderly persons institutionalized in residential facilities that provide various types of care is increasing all the time. Care is provided by caregivers who, often unknowingly, are delivering palliative care, and in doing so, are accompanying the elderly persons to their death. The aim of the present study was to investigate how terminal illness and death are experienced by caregivers. A qualitative explorative-descriptive study was carried out, featuring a phenomenological approach, in accordance with Giorgi. The sample was comprised of nine individuals who worked in residential facilities, with data collected through a semi-structured interview. Following data analysis, eight categories were defined: relationship with the elderly person; positive experiences, positive feelings, negative experiences, negative feelings, strategies, consequences and training. These categories were then divided into subcategories. It can be concluded that the caregivers experienced great difficulty when dealing with suffering at the end of life. This did not prevent them from enjoying their work, and a number of positive aspects of their relationships with the elderly were mentioned. The need to provide more support for these professionals, whether through further training or the level of psychological support provided, is also fundamental in this area of palliative care, as only in this way will individuals feel more able and confident about performing their tasks, brining greater benefit for the elderly persons.

Keywords: Caregivers. Homes for the Aged. Elderly. Palliative Care.

---

[1] Universidade do Porto, Faculdade de Medicina. Porto, Portugal.

[2] Universidade do Porto, Escola Superior de Enfermagem de Coimbra, Coimbra, Portugal.

Correspondence
Matilde Sampaio Carvalho
E-mail: matilde_carvalho@live.com.pt

INTRODUCTION

While in 2001 the population in Portugal aged over 65 years represented around 16.5% of the total population, by 2013 it had reached 19.9%. This growth means Portugal has the fourth highest proportion of elderly persons in the European Union. In 2013, there were 136 elderly persons for every 100 young people, while it is estimated there will be 296 elderly persons for every 100 young people by 2053.[1]

The longevity of populations, accompanied by various social and family changes, raises concerns about the end of life care of elderly people living in institutions.

"Aging is (...) a positive phenomenon, both for individuals and for societies, and demonstrates the progress made by mankind in economic, social and biomedical terms, based on which public policies ensuring the universal access of the population to health care have been created".[2]

Aging inevitably results in a functional, progressive and irreversible decline, as functionality in several areas is lost and will not return to earlier levels. The main consequence associated with such loss is frailty, a condition of risk for the body. Elderly people may not suffer from an explicit disease, but the risk of such diseases arising is greater than among younger people.[3]

Many elderly persons are autonomous and independent, but the risk of disease increases with age. As age advances, an increasing number of elderly persons will be faced with growing problems of autonomy and will depend increasingly on others.[2]

When independence is compromised, a social network, which can be formed from an informal network consisting of friends, family or neighbors, or a formal network, is required. The formal network will provide services which the informal network cannot, and may be provided by government institutions, welfare and charitable institutions and even private institutions.

Institutions that accommodate the elderly are known as residential facilities (RF), and are considered to be "residential facilities for older people, establishments for collective housing, for temporary or permanent use, which provide social support activities and nursing care."[4]

When an elderly person is institutionalized, it is the *ajudantes de ação direta* (direct action assistants or professional caregivers), a term used in Portugal to refer to those who care for the elderly in residential facilities, who often spend more time than anyone else with the elderly persons, replacing the absent family and resulting, inevitably, in a bond being formed between the two. The main task of such professional caregivers is to accompany the elderly person to ensure that all his or her basic needs are met, including the provision of care in hygiene, food, company, and dressing, and ensuring that the prescribed medication is taken.

During their stay in these institutions, the elderly often go from a state of independence to a state of total dependence, their frailty increases and some end up in a terminal situation. Professional caregivers must therefore provide palliative care (PC) for the elderly, whether or not they are prepared for this reality.

Professional caregivers should have training in their work area, be able to maintain their physical integrity, stability and emotional balance, and possess technical, ethical and moral skills. They undertake to establish relations of trust and dignity and to assume responsibility, and should be motivated and show empathy for the elderly.[5]

As these professionals are at the forefront of care for the elderly, it is important to understand how they deal with their growing closeness to the elderly during care and later the death of these individuals. Understanding the experiences of professional caregivers, their experiences and contributions can help to improve the responses provided to elderly persons. Studies that include informal caregivers, elderly or nurses are common in literature, but those relating to professional caregivers are scarce. The guiding question for this study was: how do professional caregivers experience terminal illness and death in residential care facilities for the elderly?

METHOD

A qualitative exploratory and descriptive study with a phenomenological approach was performed. To carry out the phenomenological approach the seven-step interpretive process described by Giorgi was used: 1. Read the entire depiction of the experience for a sense of the whole; 2. Reread the depiction; 3. Identify the transition units of the experience; 4. Clarify and elaborate the meaning that relates the constituents to each other and to the whole; 5. Reflect on the constituents according to the specific language of each participant; 6 Make the language specific in a linguistic sense or in terms of scientific concepts; 7. Integrate and synthesize comprehension in a descriptive structure based on the meaning of the experience.[6] This interpretive process expresses the possibility that the phenomenological method has access to the living world. It is an appropriate model for human, social and health sciences when the context of the experience of the subject and man as a protagonist is important.[7]

The study was conducted with caregivers in three RFs in the north of Portugal, in order to obtain rich, dense experiences of the phenomenon. The facilities had similar numbers of caregivers and elderly persons, and all three were private welfare or charitable institutions. While there was a list of RFs to whom the research request could be directed, the saturation point was reached by the third such institution with the participation of the ninth individual.

The sample was intentional, with individuals selected based on knowledge of the phenomenon under study and whether they had experienced and were able to share their understanding of the subject.[6] The nine individuals who took part in the study met the inclusion criteria, which were age (being at least 18), have worked in this area for more than two years, worked in an institution with more than 20 residents, and were freely able to participate in the study. The exclusion criteria were considered participants who did not meet all the parameters of the inclusion criteria. The selection was random, and on the day of data collection the management of the facility was requested to allow the collaboration of three professional caregivers, with the researcher not intervening in their selection.

An open interview with a semi-structured script was used. The questions were of open response type, allowing the participant to be free to respond as he or she saw fit, without having to choose predetermined responses.[8]

The script had only one guiding question: "During the time that you have worked here and have taken care of elderly persons in a terminal situation...how would you describe your experience?" The guiding question was posed only to guide the interview, rather than limit the response of the professional caregiver. [9] It was hoped that a number of topics would be addressed: the importance the professional caregiver attached to palliative care (PC); their relationship with elderly persons who they know are terminally ill and whether the caregiver talks to the elderly person about the subject or keeps his or her distance; feelings associated with caring for elderly persons in a terminal situation; involvement of the family members of the professional caregiver; the emotional support the residential facility provides following the death of an elderly person. The interview structure was validated by an experienced investigator and a pretest was conducted with one participant. As no doubts arose during this process, this interview was included in the study.

The interviews took place in January and February 2013. The interviews were scheduled based on the availability of the RFs and their staff. Before starting the interview, participants were informed about the nature of the study and the need to record the audio of the interview, the voluntary nature of participation and the guarantee of secrecy and the anonymity of the information gathered. Consent was obtained in writing.

Recording was carried out using the *Cool Edit Pro 2.1 Portable* program. Following recording the interviews were transcribed using *Microsoft Office Word* without mention of the institution to which each participant belonged.

The participants were all female, as there were no male professional caregivers in the RFs visited. Ages ranged from 32 to 55 years, with the majority of participants (five) aged between 30 and 40 years. Five participants were married, two were single, and there was one divorcee and one widow. The time spent working in the area and the time spent at the institution coincided and varied from 4 to 32 years. Most of the participants (four) had worked in the residential facility for 11 years, and the rest 4, 13, 17 and 32 years.

To obtain the results, in accordance with the Giorgi method, it was necessary to read the entire depiction provided in order to obtain a feeling of the complete interview.

It was then necessary to re-read the interviews several times, to try to understand and identify what were the transition units of the experiences reported by the participants. After reviewing the transcripts similar data was agglomerated. This conglomeration of ideas was organized into different categories, with each of these categories being considered a transition unit of the experience. This grouping of information allows researchers to find meaning according to what has been observed and recorded.[6]

The study was approved by the Ethics Committee of the Escola Superior de Enfermagem de Coimbra (the Coimbra Higher Nursing School), (Approval Nº 123-11-2012) and was later authorized by the directors of the RFs involved.

DISCUSSION

Data analysis was conducted according to the Giorgi method, where a reading was carried out of all the descriptions and interviews to achieve a sense of the whole. As such it was necessary to understand the language of all the respondents. It was then necessary to re-read several times to identify the meaning units. As these units are constitutive and not just isolated elements, an interpretation is made by the researcher, and several researchers can analyze the same set of data differently. After this phase, it was necessary to make the language of the professional caregivers appropriate for the phenomenon being studied. This step allows the categories described in the findings to be identified.[7]

From this analysis a central category emerged: the relationship with the terminally ill elderly person, in other words, how the relationship between the professional caregiver and the terminally ill elderly person can be characterized. Implicit to this category, five categories emerged, positive experiences and feelings, negative experiences and feelings, strategies, consequences and training.

In order to present an overview of the findings of the investigation, Figure 1 shows the various categories that emerged from the analysis of experiences in order to better understand the essence of the phenomenon.

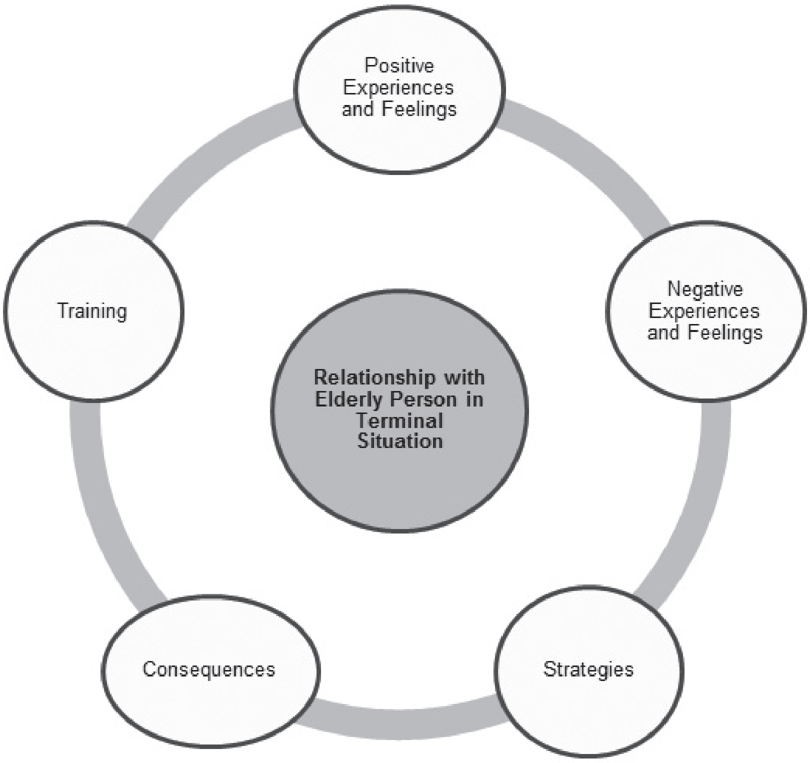

Figure 1. Analysis of phenomenon: experiences of professional caregivers in relation to the illness and death of elderly persons in residential facilities.

Having presented the overall structure of the phenomenon, the description and discussion of each category will now be provided.

Relationship with terminally ill elderly person

The professional caregivers considered their relationship with the terminally ill elderly person to be very intense, yet also something that provides great satisfaction. From this category, 14 subcategories emerged: the vulnerable other, assistance, attention, comfort, care, respect for the individual, equality, personalization, presence, meeting needs, touch, subjectivity, protection and motivation.

Vulnerable other: The resource of institutionalization is normally employed in situations where the elderly person requires great support, and, while not necessarily terminally ill, suffers from multiple morbidities, ""*(...) she had every disease you could imagine and others besides (...)*" E6, "*(...) they are so debilitated (...)*," and so they seek an institution that can support their vulnerability.

In caring for another, one should be aware of the real vulnerability of the individual. There must be a relationship between the caregiver and the person who requires care, in which the protagonist is the vulnerable person that requires help, and not the caregiver.[5] When the individual becomes ill he or she experiences a set of feelings that are complex and difficult to understand in everyday life. With disease, the frailty and vulnerability of the human condition emerge, as certain issues, such as maintaining health, independence and autonomy, are no longer within our control. Life ceases to be free and assumes limitations.[10]

In providing care, professionals should be promoters of a dignified death and carry out multidimensional monitoring of the elderly person and his or her family, expressing concern and specificity when caring for frail and vulnerable elderly persons.[11]

In learning about the debilitation of the elderly person the professional caregiver needs to adapt his or her posture to help in the best way possible.

The help given by these professionals is translated into everything they do to help the elderly, with the relief of suffering, whether physical, psychological or spiritual, being central: *"(...) ease his suffering a little (...)"* E4, even though they are aware that sometimes they cannot make it go away.

When it comes to patients in the terminal phase, the provision of assistance helps the patient to live as serenely as possible up to the time of his or her death. Assistance implies an attentive, rather than a constant presence, where the caregiver must have a listening approach and an attitude of empathy and congruence[12]: *"(…) relieve suffering, even if just a little (…)"* E2.

The attention given to a person in a situation of illness: "besides being a matter of human solidarity is an ethical imperative for all health professions."[13]

The need to provide more care to elderly patients appears to be based on the fact that most elderly persons not only need more care, but also the more frequent presence of care. According to a study by Ramos,[11] professionals pay special attention to the terminally ill and their families, and there is a greater concern for humanization and awareness in actions taken. The need to provide more attention was considered important for the comfort of the elderly patient.

This attention was justified by the participants by the fact that many elderly people can no longer speak clearly and therefore often do not ask for what they need: *"(...) especially those who do not speak and do not express themselves (...)"* E5. It is important to be truly there for the patient: "*(...) a touch, or a little word, a joke or a song, is very important. Singing something, I think, is important."* E7.

As professional caregivers understand that they are often unable to relieve the physical suffering of elderly patients, the provision of comfort itself can also be a potential help. While this comfort can be physical, the participants often referred to the importance of a human presence, with the elderly person feeling that the caregiver is there for him or her: *"(…) the simple fact of being there is a comfort (…)"* E4. *"(…) we try to position them so that they can be as comfortable as possible (…)"* E9.

At this stage, when there is no longer a cure for the disease, care should be aimed at the comfort of the patient, often through simple gestures.[14]

The professional caregivers interviewed mentioned that the care they provide to the elderly persons in this phase includes hydration, nutrition and positioning. Monitoring and encouraging the abilities and individual identity of the elderly person are also part of care.[10] *"(…) we provide the maximum amount of care (…) whether physical or psychological."* E1.

Caring for people at the end of life requires non-standardized humanized care which results from the mutual and continuous learning of the individual providing care and the person receiving it.[15]

The act of caring is seen by the professional caregiver as a technique that aims to meet the needs of elderly people with progressive disabilities and thus hopes to improve health through the act of caring itself. It was also expressed that responsibility, commitment, availability, respect and patience are part of such care.[16]

In a phase where the individual is in such a fragile situation, respect and human dignity should not be forgotten. The elderly person requires not only technical care but also the human and respectful treatment of their dignity as a human being. This was described by the study participants: *"(…) the person is there until his or her last breath (…)"* E1.

Respect for sick individuals was also mentioned in the study by Munn et al.,[17] which noted the importance of recognizing the personality of an individual at the end of life for quality of life during the process of dying in an ER. The professional caregivers in this study also referred to the importance of looking at the elderly as someone who should have quality of life to the end *"(…) it's an old person, not a rag, we have to give them the best care possible (…)"* E8.

The professional caregivers said they treated all the elderly persons equally, whether they had terminal illnesses or not, and considered elderly persons in a terminal phase as deserving the same attention and consideration as everyone else.

Time and dedication is provided in the same way for all elderly persons: *"(…) we have to treat all the elderly people equally (…)"* E5, *"(…) care and affection have to be equal (…)"* E6.

The importance of getting to know each elderly person was mentioned in the present study, as care may be customized depending on the individual in question: *"(…) it depends on each person (…)"* E3, *"It depends on the person, we have to get to know the type of personality of each person (…)*" E1.

In the study by Ferreira[18], it was found that the uniqueness of each elderly person was taken into account by the respondents. This is an important factor, as many caregivers and even the wider population consider the elderly as a single group, failing to view them as unique and heterogeneous individuals who have their own tastes, desires, aspirations and potentialities.

Fonseca[3] also refers to the importance of personalized care, describing the value of avoiding standardization, providing each elderly person with proper care in relation to the specific problems they exhibit, respecting their personal characteristics and, above all, not imposing a similar approach to all because of their apparently identical needs.

The professional caregivers mentioned that they felt just being present was something positive they could do for the elderly, and that their presence was much more beneficial to the elderly persons than the basic comfort care they could provide: *"(…) they feel that with our presence they're not alone, (…)"* E4, *"(…) to try and be there as much as possible so that they feel they have company (…)* E7.

The presence of the caregivers, along with the ability to listen to or even respect the wish for silence of the patient, can be essential to help a patient in pain to find a new meaning of life.[15] Being present helps lessen the fears of dying alone by guaranteeing a human presence.[19]

One of the major aspects of the care provided to the elderly is meeting their needs. The interviewees expressed this concern when performing their work, considering physiological needs to be very important: *"(…) I think what they really need is to eat and drink well (…)"* E8, *"(…) we're always thinking about whether they need something else (…)"* E6.

In the study by Vieira et al.[16] the participants discussed focusing much of their care on carrying out activities aimed at the basic needs of the elderly persons, seeking to promote their health. They attribute the need for care to the condition of health presented, and carry out tasks based on the medical profile of the individual, imagining that this will satisfy the elderly person.

Touching is described in the study as a way of comforting the elderly person. Taking the individual's hand is seen is an effective therapeutic approach to comfort the elderly: *"(…) sometimes taking someone's hand is a comfort (…)"* E3. *"(…) I'm a touchy feely person … I like physical contact (…)"* E9.

Touching implies entering the personal and immediate space of another, namely the person who is to be cared for. In professional caregiving, as well as in nursing, hands are used a lot, with professional caregivers touching the elderly persons on a daily basis to provide care. The intentional touch comforts and contributes to a warm relationship between the caregiver and the person receiving care. Those in a weakened state feel comforted by the touch of the professional caregiver, who in turn gives some of their attention and time.[20]

The professional caregivers said that the care they provide differs depending on the individual and that they provide subjective care, or in other words they have the same principles of action but, being individual human beings, it is obvious that the way they relate to others will not be the same and therefore their approach will differ from person to person. Fernandes[10] says that the way in which each caregiver provides care is unique as it reflects the interpersonal relationship established with the elderly person and requires a reflective attitude in which everything must be weighed, taking into account ethical, moral, professional, social and personal conduct. In the study by Vieira et al.[16] the participants also described this subjectivity when providing care. They relied on their feelings of caring, such as love, compassion, pity and affection, which unconsciously influenced their work: *"(…) it also depends, we're not all the same, each one has his or her own approach, his or her way of doing things (…)"* E3.

Protection is intuitive. The professional caregivers said that although the elderly person may be suffering they do not talk about illness and approaching death. They said that they believed talking about the subject would result in greater suffering, and hoped that it would be forgotten, considering this to be one of the best ways of protecting the individual.

To achieve this, they adopt persuasive strategies, seeking upbeat conversation topics and creating them if none exist: *"(…) that it might be nothing, that they'll get better, give them examples of cases where people have gone through the same thing and got better (…)"* E2, *"(…) don't confront them with reality (…)" E1.*

The relatives of patients also describe the importance of protecting the patient from psychological distress, noting that the revelation of prognoses brings them more anguish and can lead to depression.[21]

The professional caregivers said on a number of occasions that they did not talk about death to the elderly persons.

For them, it is important to try and motivate the elderly persons, encouraging them so that they do not become depressed about their state of health: *"(…) our job is to try as much as we can to make sure the person doesn't give up on life (…)"* E1, *"(…) tell them a joke, make them laugh, (…)"* E9. As such, they strive to install enthusiasm, encourage the elderly persons not to let despair take over, and try to meet the needs of esteem and self-actualization of the elderly.

Positive Experiences and Feelings

Of all the benefits that they could identify in their work, the professional caregivers said that they always tried to do their best when providing care to the elderly persons: *"(…) we try, I don't know, to support them in the best way possible (…)"* E5, *"(…) to do the best I can, the best that I know how, (…)"* E4. When doing the best that they can, to the best of their knowledge, the participants felt they had done their duty.

When the professional caregiver believes that he or she has performed the provision of care well, the feeling of job satisfaction can even work as a support strategy for the relief of stress.[22]

The professional caregivers said that when they perceive that the elderly person is in a situation of great frailty, there was a tendency to grow even closer to that person: *"(…) I get even closer because I see that the person is approaching the end, (…)"* E1, *"(…) when I understand that, it often makes us close friends, (…)"* E2.

They considered it to be of the utmost importance to continue or even increase contact, so that the elderly persons do not feel neglected, isolated or alone.

With the passing of time, the professional caregivers considered themselves better prepared to act and perform in a range of situations: *"(…) it's harder to deal with certain situations (…) with years in the job, today I feel that I'm cooler and calmer under pressure (…)"* E5. They consider that their experiences enrich them and help them to improve and grow, making them more confident in the performance of their roles.

Gómez[23] states that to be a caregiver, investment, great preparation and availability are required.

Affection, generally associated with family relationships, also appears in the relationship between the professional caregiver and the elderly person: *"(…) they end up becoming our family (…)."* E1, *"(…) our warmth is really the best."* E7.

The experiences collected here demonstrated a great and genuine satisfaction when taking care of the elderly, leading to the creation of bonds of affection with such individuals. Given that a residential facility is normally an institution where there is not a high turnover of employees or residents, it is normal that these ties are created. A bond can be registered with the elderly person that makes him or her remember family ties.

The affection that arises in these relationships can often be justified by a perception of need among the elderly, which is due to a lack of family attention. This emotional involvement, as a rule, will cause greater suffering among the care professional when the elderly person dies.[24]

Due to the strong bonds created between caregivers and elderly, it is understandable that the professional caregiver nurtures feelings of affection for the elderly person in their care. Often the affection transmitted by care can be seen as a type of reward for the hard lives they have had, and the sense of being abandoned by their families.

In cases where the elderly person is sick, affection is seen as a treatment approach in some situations: *"(…) I think better than medication, better than food, is affection (…)"* E7, *"(…) these people need affection, most of all, affection (…)"* E5.

Affection together with tolerance is seen by health professionals as a pre-requisite for a good caregiver/elderly person relationship. The care and affection that are given to the elderly person are fundamental for creating the feeling that the caregiver has fulfilled his or her duty. Affection is a major factor in a humane relationship, yet caregivers can never forget their role as caregivers in an institutional context.[24]

Negative Experiences and Feelings

The professional caregivers also described the difficulties they experienced. There are a number of such difficulties, but interacting with an elderly person in the terminal stage of life was one of the main problems described: *"(…) dealing with this type of elderly person is very difficult (…)"* E5, *"(…) it has taken a lot out of me, as it happens it's taken a lot out of me."* E9. In a study by Barbosa et al.[25], interaction with the elderly person in a terminal phase was also described as difficult. The same study also described difficulties such as a lack of time, a shortage of human resources, the emotional and physical impact, the difficulties of organization and the planning of activities, interaction with the families of the elderly person, the limited involvement of the family member in the dynamic of the institution, communication with the elderly person, the lack of knowledge about disease, and dealing with behavioral disturbances.

Other difficulties experienced by the professional caregiver registered in literature are: tiredness, stress, worry, anxiety, the appearance of disease/symptoms, alterations to daily life and variations in self-esteem, negatively affecting the care provided and quality of life.[26]

The accumulation of a number of tasks and possible reductions in the number of professional caregivers in institutions can also be an obstacle for the provision of care. Some participants considered that the shortage of time often affects the care they provide, as they are unable to spend as much time with the elderly person as they would like *"(…) we don't have the time to dedicate more time to these people (…)"* E5, *"(…) we don't have much time to spend with them (…)"* E1.

The inexperience at the beginning of a career or even in complicated situations was also described as a negative experience. *"(…) at the start it was hard on me (…) because I had to train, I wasn't trained yet (…)"* E1. In the study by Marshall et al.[27], the team describes how certain members avoid caring for elderly persons at the end of life, citing a lack of knowledge and experience in the area. For this reason, it may be difficult for them to deal with elderly persons in terminal situations, which was also mentioned by the professional caregivers in the present study.

Caring for elderly persons in a terminal situation brings suffering, as the caregivers can create bonds with the individuals. They describe how difficult it is to watch their suffering while in many cases being unable to help. Much of this suffering is related to the impotence felt when seeing another suffer and not being able to do anything to relieve the pain: *"(...) it's really hard to see other people suffering (...)"* E4. Suffering is a feeling that accompanies the human being and will appear during life in one form or another as a consequence of the frailty of the biological being and the sensitivity of the psychological being.[12]

The professional caregivers in the present study often felt frustration: *"(...) we can't do much (...)"* E6, *"(...) there's nothing we can do, (...)"* E5.

This frustration is also felt with elderly patients with conditions of dementia, due to the impotence that caregivers feel when trying to interact with the elderly persons, or trying to understand their needs, or not knowing how to overcome difficult situations.[25]

Sadness was also present in the provision of care due to the presence of suffering and death: *"I feel sad (...) it's very hard, getting home and still thinking about that person (...)"* E1, *"(...) you get attached to them and then you feel sadder (...)"* E4. They described feeling sad and depressed on some days at work.

Casmarrinha[21], when studying relatives of terminally ill patients, also noted the sadness they felt, due to fear of the day of the death of their family member. Although the relatives interviewed described feeling sadness, they said they tried to hide such feelings in front of the patient. The sadness felt stemmed from the awareness of the real consequences of the disease, and the anticipation of the grief they would experience.[21]

Strategies

In such a demanding profession, sharing and mutual assistance between caregivers is crucial, as well as team spirit, which benefits the whole team as well as the elderly themselves, who receive better care.

Mutual help between colleagues can take the form of opinions on a case: *"(...) I like someone to accompany me (...) so we can exchange ideas (...)"* E8, *"(...) I think it was important to try to explain and help."* E9.

The experiences gathered emphasized that collaboration between the team promotes learning among professionals. Mutual assistance, as well as producing a good working environment, can influence the quality of life of the professional caregiver and the quality of service provided to the elderly. Teamwork is seen by the professional caregiver as a protective factor to prevent situations that can be both physically and emotionally disturbing.[18] Parece[28] states that teamwork allows moments of reflection on a number of situations and issues, which should be considered so that caregivers can plan and outline appropriate intervention strategies at each moment together.

The family support felt by caregivers was considered a positive factor, as they know that their families will always be there for them and understand that their work is emotionally draining. *"(...) I have a family that supports me in this (...) they know that our work, as well as being physical, is much more emotional."* E9, *"(...) I get home and tell my husband (...)"* E6.

A study by Fernandes,[10] described family support as support for the individual, as they get to know their family members on a deeper level, knowing how much they can help them.

This study referred to the benefits of creating time for debate through the exchange of experiences: *"(...) there were a lot of debates even within the group of colleagues, because they help us a lot (...)"* E9. For the professional caregivers it is more helpful to listen to those who are comfortable with the subject and who have experienced similar complicated situations.

Creating spaces of contact for exchanging experiences between the elements of multidisciplinary teams who provide care at the end of life would be beneficial.[28]

Consequences

The experience acquired through years of professional activity is considered by the participants to be of added value. It has made them more capable, more confident and more mature in their work: *"We've been through some bad experiences and life teaches us and prepares us (…)"* E8, *"(…) we learn over time, (…)"* E1.

Experience allows skills to be learnt when carrying out professional tasks, which result from experience gained over time and interaction with colleagues.[25]

The experience acquired through work and interaction with other caregivers is seen by some professionals as sufficient for making up for a lack of academic qualifications in terms of the performance of the professional duties inherent to the profession.[26]

The professional caregivers stated that it was impossible not to take some of their concerns home with them: *"(…) we sometimes take our problems home with us (…)"* E2, *"(…) it's difficult to switch off (…) we don't have a little button (…)"* E4. Parece[28] described how professionals who witness deaths, despite knowing that these form part of the natural cycle of life, often carry these deaths over into their day-to-day life. When a death occurs, the professional often imagines that it could be the death of a member of his or her own family, and this frightening experience often affects their daily life.

While not suggesting it is easy to deal with such occurrences, professional experience in caring for the elderly means that the professional caregiver can prevent their job from influencing their quality of life.[18]

Training

It is considered important to be trained in their professional area, in terms of the importance of knowing, learning and possessing knowledge. Although many caregivers can be employed by RFs without any training, they recognize the importance of improving techniques, learning new concepts and approaches for dealing with specific situations, considering this to be an asset for the day-to-day care of the elderly, which is a potentiating factor for improving their professional and personal satisfaction: *"(…) we should have the proper preparation to know that we're here to provide care (…)"* E1, *"(…) the more training we have, the more information (…)"* E9.

The study by Ribeiro et al.[29] states that caregivers with more education are more able to assist the elderly in more complex situations, such as medication dosage, and receiving and delivering technical instructions. With this greater capacity, elderly persons are encouraged to maintain their autonomy and well-being.

Training can also be viewed, according to the professional caregiver, as a means of preventing, in tandem with other factors, the appearance of burnout.[18] The same author states that, whether as a preventive measure or not, training should be a priority for institutions, especially for professional caregivers. Such training should aim, distancing itself from specific topics such as PC, a theme explored in this study, to raise awareness of the importance of good interpersonal relationships between the employees and the elderly.

In terms of knowledge of their professional area, the participants described having undergone a number of training programs in which PC was studied, meaning that in theory it is not an unknown term: *"(…) I've had a number of training sessions about this."* E1, *"(…) I'm now having training about this, (…)"* E9.

Castanheira[30] concluded that professional caregivers generally had training in geriatrics and, over the course of their careers, had the opportunity for continuous training. Much of the training in geriatrics occurred after the beginning of their careers. The initial lack of training in this professional area can be explained by the fact that most caregivers do not initially view themselves as carrying out such work in the medium and long term.

Refreshing knowledge is considered beneficial. Updating knowledge, monitoring changing techniques and learning new approaches is supported by several authors. It is considered beneficial that institutions promote such training and when they are unable to do so, facilitate and encourage the participation of their employees in these programs. *"(…) I like to refresh and update my knowledge because there are always new things, new experiences (…)"* E3.

Continuous training is considered useful by all the caregivers, as it makes the tasks they have to perform easier.[30]

The PC services inserted in the Rede de Cuidados Continuados Integrados (Continuous Integrated Care Network) are aimed at the entire population. There is no specific connection, however, with the social response provided by the Emergency Room (ER). Although the PC network in Portugal does not cover everyone who requires such care, hospital teams, inpatient units and home CP support teams are available. These could provide the support that the ER requires by providing external assistance in palliative care. This would benefit the elderly persons as much as the professional caregivers, who would be less overloaded by feelings of impotence when faced with the suffering of the elderly. The Estratégias para o Desenvolvimento do Programa Nacional de CP (the Strategies of the National PC Development Program) plan aims to provide PC to all institutionalized patients, so improving local level interconnection with support entities in order to understand the needs of PC. Another aim of the program is to facilitate the accessibility of PC teams to the respective entities, and of PC training courses for caregivers and workers in these services.[31]

Limitations

Despite the richness of these findings, they cannot be generalized as they are valid only for the group and context studied.

The bibliography of this study area is lacking, as the majority of studies are directed at family members, nurses and the elderly, but rarely at professional caregivers.

During the interviews, it was noted that the professional caregivers are not used to being heard and the recording was an intimidating factor. This was certainly the reason why some of the answers are rather succinct and provide little content in response to the questions.

CONCLUSION

The participants felt a close relationship with the elderly, marked by intense experiences, some of which are less than positive due to the suffering of the elderly. It was hard for the professional caregivers to talk about death, as they try to protect the elderly persons as much as possible, promoting hope and reducing suffering. To this end, presence, touch, support and non-withdrawal are essential.

By experiencing these situations, feelings such as fear, sadness and frustration emerge, as well as affection, fondness and pride in the roles they perform.

To address these difficulties, factors such as the team spirit created between professionals and asking colleagues who have gone through similar situations are important, as well as family support.

In terms of consequences, experience, memories of deceased elderly persons and taking problems home were mentioned.

The experiences described were rich, with the originally described objectives being achieved.

The profession of professional caregiver is reflective of the current job market due to the growing phenomenon of human aging. For this reason, these professionals merit our attention in further studies.

More investigations should be carried out in this area, focusing on the difficulties of professional caregivers, due to the potential usefulness of training programs.

Also in relation to training, the stress and emotional strain that professional caregivers suffer should not be overlooked and should be the target of investment in training programs that focus on this area.

The relationship between the professional caregivers and the elderly persons should also be the focus of investigation and training.

Improving the response of professional caregivers to elderly persons adds dignity to the care provided and, lastly, improves the future of each one of us.

REFERENCES

1. Carrilho M. A Situação demográfica recente em Portugal. Rev Est Demogr [Internet] 2015 [acesso em 16 jun 2016];(54):57-107. Disponível em: https://www.ine.pt/xportal/xmain?xpid=INE&xpgid=ine_publicacoes&PUBLICACOESpub_boui=210786633&PUBLICACOESmodo=2
2. Cabral M, Ferreira P, Silva P, Jerónimo P, Marques T. Processos de Envelhecimento em Portugal. Lisboa: Fundação Francisco Manuel dos Santos; 2013.
3. Fonseca AM. Cuidados e demência na terceira idade: manual prático. Amares: ADRAVE; 2014.
4. Portugal. Ministério da Solidariedade e da Segurança Social. Portaria 67/2012, de 21 de março de 2012. Define as condições de organização, funcionamento e instalação das estruturas residenciais para pessoas idosas. Diário da República, nº 58, Série I.
5. Fernandes S. Vivências em lares: diversidade de percursos em estudo de caso [dissertação na Internet]. Porto: Universidade Portucalense Infante D. Henrique; 2010 [acesso em 20 jun 2016]. Disponível em: http://hdl.handle.net/11328/219
6. Streubert HJ, Carpenter DR. Investigação qualitativa em enfermagem: avançando o imperativo humanista. 2ª ed. Loures: Lusociência; 1999.
7. Andrade C, Holanda A. Apontamentos sobre a pesquisa qualitativa e pesquisa empírico-fenomenológica. Est Psicol [Internet] 2010 [acesso em 22 fev 2016];27(2):259-68. Disponível em: http://www.scielo.br/pdf/estpsi/v27n2/a13v27n2.pdf
8. Fortin MF. O processo de investigação: da concepção à realização. Loures: Lusociência; 1999.
9. Freitas S. A pesquisa fenomenológica em psicologia. In: Baptista MN, Campos DC. Metodologias de pesquisa em ciências: análise quantitativa e qualitativa. Rio de Janeiro: Livros Técnicos e Científicos Editora; 2007. P.209.
10. Fernandes IMR. Quando o enfermeiro se torna doente: acedendo à experiência vivida [tese na Internet]. Lisboa: Universidade de Lisboa; 2012 [acesso em 11 fev 2015]. Disponível em: http://hdl.handle.net/10451/7423
11. Ramos RCGB. O idoso institucionalizado em fase terminal [dissertação na Internet]. Porto: Universidade do Porto; 2014 [acesso em 22 jun 2016]. Disponível em: http://hdl.handle.net/10216/78783
12. Pacheco S. Cuidar a pessoa em fase terminal. Loures: Lusociência; 2002.
13. Gameiro MGH. O sofrimento na doença. Coimbra: Quarteto Editora; 1999.
14. Frias C. A aprendizagem do cuidador e a morte, um desígnio do enfermeiro em formação. Loures: Lusociência; 2003.
15. Alvarenga MIC. A comunicação na transferência dos cuidados curativos para os cuidados paliativos [tese na Internet]. Lisboa: Faculdade de Medicina de Lisboa; 2008 [acesso em 23 mai 2013]. Disponível em http://hdl.handle.net/10451/1114
16. Vieira CPB, Gomes EBF, Fialho AVM, Silva LF, Freitas MC, Moreira TMM. Concepções de cuidado por cuidadores formais de pessoas idosas institucionalizadas. REME Rev Min Enferm [Internet] 2011 [acesso em 05 dez 2015];15(3):348-55. Disponível em: http://www.enf.ufmg.br/site_novo/modules/mastop_publish/files/files_4e8da8407cc5a.pdf

17. Munn J, Zimmerman S, Hanson L, Williams C, Sloane P, Clipp E, et al. Measuring the quality of dying in long term care. J Am Geriatr Soc [Internet] 2007 [acesso em 27 nov 2015];55(9):1371-9. Disponível em: http://www.ncbi.nlm.nih.gov/pubmed/17915342.

18. Ferreira MEM. Ser cuidador: um estudo sobre a satisfação do cuidador formal de idosos [dissertação na Internet]. Bragança: Escola Superior de Educação do Instituto Politécnico de Bragança; 2012 [acesso em 20 jun 2015]. Disponível em: http://hdl.handle.net/10198/7936

19. Waldrop D, Kirkendall A. Comfort Measures: a qualitative study of Nursing Home- Based End-of-Life Care. J Palliat Med [Internet] 2009 [acesso em 12 nov 2015];12(8):719-24. Disponível em: http://www.ncbi.nlm.nih.gov/pubmed/19586390

20. Catita P. As representações sociais dos enfermeiros do serviço de urgência face ao doente idoso [tese na Internet]. Lisboa: Universidade Aberta de Lisboa; 2008 [acesso em 24 jun 2016]. Disponível em: http://hdl.handle.net/10400.2/701

21. Casmarrinha M. Familiares do doente oncológico em fim de vida dos sentimentos às necessidades [tese na Internet]. Porto: Universidade do Porto, Instituto de Ciências Biomédicas de Abel Salazar; 2008 [acesso em 23 fev 2015]. Disponível em: http://hdl.handle.net/10216/7169

22. Batista P. Stress e Coping nos enfermeiros dos cuidados paliativos em oncologia [tese na Internet]. Porto: Universidade do Porto, Instituto de Ciências Biomédicas de Abel Salazar; 2008 [acesso em 19 out 2015]. Disponível em: http://repositorio-aberto.up.pt/bitstream/10216/19398/2/Paula%20Batista%20Mestrado%202008.pdf

23. Gómez J. Impacto de um programa de relaxamento na percepção do stress nos cuidadores formais de um Lar do Concelho de Águeda [Dissertação na Internet]. Porto: Instituto Politécnico do Porto, Escola Superior de Tecnologia de Saúde do Porto; 2010 [acesso em 26 fev 2015]. Disponível em: http://recipp.ipp.pt/bitstream/10400.22/729/1/DM_JanethGomez_2010.pdf

24. Marques C. O Burnout nos ajudantes de ação direta que trabalham em lares residenciais para idosos no distrito de Viseu [dissertação na Internet]. Viseu: Universidade Católica Portuguesa; 2013 [acesso em 31 jan 2016]. Disponível em: http://hdl.handle.net/10400.14/13585

25. Barbosa A, Cruz J, Figueiredo D, Marques A, Sousa L. Cuidar de idosos com demência em instituições: competências, dificuldades e necessidades percepcionadas pelos cuidadores formais. Psicol Saúde Doenças [Internet] 2011 [acesso em 18 dez 2012];12(1):119-29. Disponível em: http://www.scielo.gpeari.mctes.pt/pdf/psd/v12n1/v12n1a08.pdf

26. Colomé I, Marqui A, Jahn A, Resta D, Carli R, Winck M, Nora T. Cuidar de idosos institucionalizados: características e dificuldades dos cuidadores. Rev Electr Enferm [Internet] 2011 [acesso em 22 abr 2015];13(2):306-12. Disponível em: http://www.revistas.ufg.br/index.php/fen/article/view/9376/9637

27. Marshall B, Clark J, Sheward K, Allan S. Staff perceptions of End-of-Life Care in aged residential care: a New Zealand perspective. J Palliat Med [Internet] 2011 [acesso em 09 jan 2016];14(6):688-95. Disponível em: http://www.ncbi.nlm.nih.gov/pubmed/21495851

28. Parece A. Vivências dos enfermeiros relativamente a cuidados post mortem em unidades de medicina [dissertação na Internet]. Lisboa: Universidade de Lisboa, Faculdade de Medicina; 2010 [acesso em 02 fev 2014]. Disponível em: http://hdl.handle.net/10451/2432

29. Ribeiro M, Ferreira R, Ferreira E, Magalhães C, Moreira A. Perfil dos cuidadores de idosos nas instituições de longa permanência de Belo Horizonte. Ciênc Saúde Coletiva [Internet] 2008 [acesso em 02 mar 2016];13(4):1285-92. Disponível em: http://dx.doi.org/10.1590/S1413-81232008000400025

30. Castanheira C. Auxiliar de Acção Directa: um estudo sobre traços de personalidade, valores e satisfação profissional [dissertação na Internet]. Lisboa: Universidade de Lisboa; 2013 [acesso em 12 mar 2016]. Disponível em: http://repositorio.ul.pt/bitstream/10451/10398/1/ulfpie046340_tm.pdf

31. Portugal. Serviço Nacional de Saúde, Unidade de Missão para os Cuidados Continuados Integrados. Estratégia para o Desenvolvimento do Programa Nacional de Cuidados Paliativos: Rede Nacional de Cuidados Continuados Integrados 2011 –2013 [Internet]. Lisboa: SNS; 2010 [acesso em 20 dez 2015]. Disponível em: http://www.arslvt.min-saude.pt/uploads/document/file/668/cuidadospaliativos_1-1-2011.pdf

Received: September 10, 2015
Revised: May 31, 2015
Accepted: July 26, 2016