COMPETENCE AND COMPASSION: KEY ELEMENTS OF PROFESSIONAL CARE AT THE END OF LIFE FROM THE CAREGIVER´S PERSPECTIVE

Abstract

In the act of caring for and helping people in the end-of-life process, the professional who provides care and assistance must know how to maintain a relationship of closeness, empathy and compassion for the pain and suffering of the person who is going to die. The objective was to understand, elaborate on and characterize the key elements of end-of-life care of patients from a caregiver´s perspective through a qualitative phenomenological multicenter study. Participants were caregivers who had lost a family member at least two months but less than two years in the past. The techniques used were five discussion groups and forty-one in-depth interviews, which included a total of eighty-one participants. To analyze the information, a protocol developed by Giorgi was followed. Two dimensions or units of meaning, with sub-dimensions, emerged: 1) Technical competence, with the sub-dimensions "Control of symptoms" and "Continuity of care"; and 2) Compassion, with the sub-dimensions "Effective/affective communication," "Attitudes of kindness and closeness towards the patient and the family" and "Generosity and personalized flexibility of care." Assistance at the end of life requires the proper preparation of professionals who care for these patients, in addition to a compassionate attitude on the part of professionals and the people accompanying the dying person, that fosters a more humanized and dignified treatment in the dying process.

Keywords: end of life, professional care, competence, compassion, caregiver, qualitative study

INTRODUCTION

Death is an inevitable drama of human life; in general terms, human beings suffer more from the possible death of their love ones than their own[1]. Generally, the person who is at the end of life is accompanied by a very close relative—someone who is their caregiver during the entire terminal illness and who has taken on the responsibility for meeting their physical and emotional needs[2].

The basis of assistance at the end of life is determined by the ability to be responsive and provide the necessary resources, both to the patient and the caregiver, which allow them to regain some control and face this situation of suffering in the face of death[3]. The care offered to patients at the end of their lives must be humanized care. The treatment that these patients receive must use a comprehensive approach, that is, it must be comprehensive care focused on all aspects of the person[4].

The act of caring for and assisting terminal patients implies a series of actions on the part of the professionals who care for these patients, always with consideration of their family member. Technical skills are essential, but so are intelligent, emotional and attitudinal actions[5].

It is necessary that professionals who care for patients have certain attitudes that allow them to know how to maintain a relationship of closeness, empathy and compassion regarding the pain and suffering of the person about to die[6]. Feldman and Kuyken defined compassion as "a basic sense of caring, sensitivity and openness to one's own suffering and towards others, and the genuine intention to try and prevent it." Compassion is a multi-textural response to pain, sadness and anguish. Compassion includes kindness, empathy, generosity and acceptance. Above all, compassion is the ability to open oneself to the reality of suffering and aspire to its healing "[7]. Patients and relatives express that in order to significantly improve the manner of facing this last stage of life, it is necessary that the care received be as personalized as possible, which is accomplished by facilitating effective communication between the multidisciplinary team and them[8, 9].

In turn, there are technical competencies, understood as the set of knowledge, skills and attitudes that facilitate excellent medical practice[10]; applied throughout the evolutionary process of treatment until the end of life. These competencies can help control the different symptoms of each stage and meet the patient's required needs[11]. The control of symptoms at all levels of care and the continuity of care[12] should be guaranteed, perceived as "the agreement of all services related to health care, regardless

of where they are received, so that they are synchronized and reached a common goal without conflicts." This continuity must be experienced by the patient[13].

Caregivers and other family members feel insecure and anxious about what they experience in these difficult and uncertain times[14]. Therefore, taking into account the comprehensive care that patients should receive at the end of life and the fact that these patients are accompanied by their caregivers, we aim to understand, illuminate and characterize the key elements of health professionals' behavior toward patients at the end of life from the perspective of the caregivers.

THE STUDY

Study design

This qualitative study was based on the paradigm of hermeneutic phenomenology according to Van Manen's model[15]. This model allows the study of people's non-conceptualized experiences and of the meaning of these experiences. That is, it attempts to study the meanings that people assign to their experiences by describing, understanding and interpreting the phenomena lived, thereby analyzing the dimensions involved in human care[16]. Therefore, this approach aimed to perform an in-depth investigation of the end-of-life care provided to patients[17].

Participants

The inclusion criteria were primary caregivers of persons who had died more than two months but less than two years in the past. This time frame was chosen because the initial shock of the grieving process was taken into account, thus leading to the decision not to include any informant who had been mourning for less than 2 months since the passing of their loved one. We also did not want to trigger any resurfacing of unresolved or pathological pain, which is why persons whose loved ones had passed more than 2 years ago were excluded. On several occasions, these exclusion criteria led to rejecting informants with a wealth of information on death-related experiences that would have been useful for the study. The death could have occurred as a result of an oncological disease, chronic pathology or any degenerative pathology, provided that the patient had received care in a center of the public health system. The death could have occurred in any hospital unit, including an emergency department, in a primary care center or at home. Family caregivers were excluded if their relative passed away outside of the timeframe indicated or if any of the circumstances of their relative's death did not fully conform to the description above.

Selection of participants

This multicenter study was conducted in five provinces of Spain. Intentional sampling was used to select participants whose circumstances were representative of the study objective, thus contributing to different caregiver perceptions according to the circumstances in which the death of their relative occurred[18]. The participants were recruited via telephone or directly by the referral of health professionals who had participated in the care process of terminally ill patients. Throughout the recruitment period, constant feedback and coordination were maintained among researchers and referral professionals.

A total of 81 participants were involved in the in-depth interviews and the discussion groups. Participants had an average age of 52.75 years, with a minimum age of 42 and a maximum of 72. The average time since the death was 9.88 months (SD = 6.85). A total of 5 group discussions with 40 participants and 41 in-depth interviews were conducted. The sociodemographic characteristics of the participants are presented in Table 1.

Table 1. Sociodemographic variables of the participants

Data Collection

The data collection period was from January 2013 to June 2014, and the analysis was conducted from January 2013 to December 2016. The researchers were trained and prepared specifically in the various techniques by staff experts. The group discussions (GD) began first; once these were finished, the in-depth interviews began. The final number of discussion groups and the number of study participants were determined based on achieving data saturation and obtaining proportional data from the different regions.

The opening question of the discussion group was "How do you think the person you assisted in the process at the end of life felt?" and the hidden script of the in-depth interviews that the researchers knew beforehand included the following: “How do you think the patient felt about the care received?”; “How did he or she feel about the care received from the professionals?”; and “Do you think he or she had emotional support from the health team?” We also included a question for people who, at some point in the process, had been referred from a medical specialty to the palliative care program: “How was the palliative care referral like?”

The discussion groups were held in meeting rooms in health centers, with an approximate duration of 90 minutes each. Two researchers participated in the groups, one of them leading the discussion and a second one taking notes on the observations and incidents that arose during the discussion. Records of the discussions were kept in a field notebook designed for that purpose.

The in-depth interviews occurred in the nursing offices of the different health centers and in the participant's home, with the researcher moving from one place to another to conduct them. The interviews lasted approximately 45 to 60 minutes.

Before the beginning of either technique, informed consent and voluntary collaboration were requested from the participants. The various discourses that occurred during the different techniques used were recorded in audio format for later transcription and analysis.

Ethical considerations

This study received the authorization of each of the ethics committees of the different provinces in which the study was developed. The participants were informed verbally and in writing of the purpose of the study, and their informed consent was obtained in a document designed for that purpose. The confidentiality and anonymity of the participants was maintained at all times with respect for the bioethical principles of the Helsinki Declaration. In the same manner, the regulations in effect in our country regarding the official data protection of material collected from discussions were followed.

Data analysis

To analyze the information from the testimonials from the discussion groups and in-depth interviews, a protocol developed by Giorgi (1997), characterized by the development of a series of topics and subtopics, was used. The protocol consisted, first, of a series of phases; after the literal transcription of testimonials was accomplished, an in-depth reading was made. Second, another reading was performed, and the most relevant units of meaning that emerged from the testimonials were extracted. Once all units of meaning were identified, they were regrouped into more general categories or dimensions that brought together smaller units of meaning that shared a commonality. In a final phase, the content of each of the categories and dimensions was interpreted based on the lived experience or phenomenon. ATLAS.ti 6.0 software was used to aid in the analysis of the testimonial data collected from the interviews and to organize the categories and obtain the corresponding nodes.

Regarding the validity of the results of the analysis, to control the biases derived from the heterogeneity of the data and from the different viewpoints of the informants, we used methodological and subject triangulation.

RESULTS

In the analysis of the discourses on both sides, two dimensions or units of meaning emerged with sub-dimensions, all under a broader category of family and professional care, as presented in Table 2. These two dimensions were Technical competence and Compassion.

Table 2. Key elements of professional care: Dimensions and sub-dimensions

Dimension 1: Technical competence

- *Control of symptoms:*

Bearing in mind that the primary objective for people in the final phase of life is comfort and well-being, informants repeatedly mentioned the value of having the basic resources needed for care, such as timely medication, support resources, and the possibility of having professionals available when, despite the prescribed treatment, distressing symptoms appeared, such as dyspnea or pain.

Well, the truth is that everything my father needed he had, and the truth is that everything worked very well, equipment, medicines. They have never, ever given me trouble acquiring morphine or patches, or anything ever. (...) I think that he died with the satisfaction of being cared for (G.D. 2).

Him, no. On the contrary, no complaints. The family doctor was always there with whatever thing I had to bring him, because they made things easier for us at first or at the last minute; if he felt bad, he [the doctor] would come quickly (E. 37).

- *Continuity of care*:

Continuity of care, in terms of both available healthcare resources and its focus on treatment approach, is a need that, when satisfactorily addressed, reduces feelings of insecurity and abandonment, even when the person at the end of life is deteriorating with regard to weakness and dependence.

We are very grateful for home care, with the family doctor who came every time we needed him, and urgencies occurred many times (GD 2).

Yes, yes, of course, cared for, yes. Every time I called the doctor, there he was, the nurses were the same ... indeed; I think they would make everything available to him within his reach (E. 3).

It was important to the informants that non-health professionals (administrators, cleaning staff, caretakers, radiology technicians, etc.) also addressed the patient and family in a cordial and respectful manner and did not introduce elements that could have raised doubts or suspicions regarding the care or the professionals. Care pertains all professionals. All are perceived individually but also as a whole, and from that whole comes the experiences perceived by caregivers and patients.

Well, regarding the professionals and care for my mother, they were spectacular —nurses, cleaners, doctors, everyone, everyone (G.D. 2.)

At the hospital? Excellent. In our case, excellent. The staff, everything. From the oncologists to the cleaner. At least in our case, it was very good, very good, very good (E. 2).

However, the reports by the caregivers illuminated quite different findings regarding the care received in emergency services. The families complained about the suffering generated by the absence of specific protocols that considered personal fragility. The families perceived a serious sense of abandonment and helplessness within hospital emergency care settings. This was one of the most dysfunctional areas of the system with regard to palliative care.

The only thing is that in emergencies, sometimes, because you meet young people, you take them and tell them what they should do. ... Because of their lack of experience, because they have not worked long or not have self-confidence, they always go and get other doctors. ... Sometimes, yes, we did get angry! So, then I think there should be one more step ... a smaller step, not this protocol they say they must follow (E. 2).

Dimension 2: Compassion

- *Effective/affective communication:*

Effective communication, according to the caregivers, should include active listening as its primary element. Patients appreciate when caregivers are attentive, calm and not pressed for time and ask for such interactions; they also prefer that caregivers refrain from using large, incomprehensible words. Furthermore, effective communication is the satisfaction expressed when, at the end of life, what we have called "affective communication" occurs. With regard to affective communication, the informants highlight the value of the link with the professional and the deep feeling that the professionals are committed to easing the suffering of the patient and family by reducing it as much as possible.

Man, he was very happy with the oncologist. ... And they were like friends and when they both got cancer, it turned out that they knew him too, and he said that he loved entering that room because he knew about his illness, and that you had to talk about other things and ... and very well. He has taken it well (E. 2).

"They relieved him a little, that is, in the way he treated her ... the smile, the treatment, that you say something to him, that you talk to him and listen to him. ... For us, that has been very positive (E. 8).

- *Attitudes of kindness and closeness towards the patient and the family:*

The sense of security for patients and families is greater when the relationships established by professionals with the sick person and their caregivers include basic respect, kindness and closeness. When patients and families encounter a hostile and strange environment, kindness and closeness are implicit components of a safe and familiar environment that generates tranquility and confidence.

They have been there, and I am very happy to be in this center. It was familiar (E. 20).

Very well, he has had a good experience. Look, very good. In all the units, we have been very well treated, but 10 was amazing. We have not lacked anything; the only thing they could not give was health, because the time came (E. 35).

Contempt and indifference are attitudes that generate intense suffering. The testimonials expressed pain and humiliation when treatment was discourteous and lacked respect and sensitivity. To the caregivers, work overload was no excuse for emotional distance and arrogance, much less for ignoring suffering.

I, already desperate, did not know who to call, and one was there at the door, and she says, "Ma'am, we're completely over capacity," and she shut me out (E. 35).

Look or go down yourself or call the nurse on duty. My mother will not suffer any more like this because I do not want that, because my mother is a human being. I have two dogs, and I would never allow them to suffer that way, especially when there are things you can give so that she does not suffer (E. 18).

- *Generosity and personalized flexibility of care:*

Although safety protocols and the functional structuring of services are essential elements for the management of care in health organizations, the informants reported that what made them feel safe and assisted was a level of care that adapted to the patient's circumstances. The testimonies reflect the generosity and flexibility of professionals in certain circumstances, which leads to personalized attention adapted to the needs of patients and their families.

The nurses approached us when they saw something odd and they got involved, but in a good way, and they mediated. I slept many nights in bed with [him]. When the janitors came in and they saw us in that small bed, they put on the door: "Just Married, Do Not Disturb." We had a good time at the hospital; they were wonderful (E. 18).

Yes, yes, visiting hours weren't restricted or anything. Even my sister and I, we took turns being there and we even stayed on Saturday, my three sisters and I, with a cousin of mine, and that's it, no problems or anything (E. 37).

DISCUSSION

Two contrasting experiences were clearly articulated. On the one hand, caregivers reported pain and suffering, experiences marked by a lack of sensitivity by professionals and a lack of preparation. Conversely, participants shared stories of the attitudes demonstrated by the professionals towards ethical care, personalized care, and interventions to assist and alleviate the suffering of the patients at the end of life and the suffering of their relatives, in a genuinely humane and sensitive manner.

The basic objectives of care at the end of life are high quality of received care, comfort and well-being[19]. The findings are consistent with those of other studies reporting that the control of symptoms is a fundamental element of the experience of disease[20, 21] and that early care by health professionals can reduce the intensity of symptoms[22]. When this occurs, it not only improves the quality of life of patients but also reduces the worries and suffering of the caregiver, thereby reducing the burden of these[23]. A frequently cited explanation for situations in which the control of symptoms is absent or reduced is a lack of continuity of care, as reflected in the emergency services. This lack of continuity may refer to the physical, psychological or spiritual care that patients need and causes insecurity at the end of life, according to the informants[24].

As we have can read in the discourses, it was quite important to the informants that the work be coordinated using interdisciplinary teams[25]. This approach goes beyond the multidisciplinary approach in which there may be many professions and professionals, each contributing specific knowledge and skills in isolation without interaction. This system, which may be effective in some situations, is not effective for the management of complex situations, such as patient care at the end of life. It is generally a complex process[7] that requires attention adapted to the needs of the person and their circumstances, as observed in the transcripts[4]. We agree with other authors that the team must practice internal flexibility, incorporating creative capacity into care. If we have an adequate acquisition of knowledge and skills, this kind of attention can be dispensed in any frame of the healthcare activities[26].

Another fundamental element that was important to informants and was reflected in many of the testimonials was the ability to communicate in all its complexity[27]. The manner in which the patient is informed of his or her situation will largely determine the future of the patient. From the diagnosis until the end of the patient's days, many events are based on information received qualitatively and quantitatively[5]. Randomized studies have demonstrated that learning communication

skills may have a positive effect on both the giver and the receiver of bad news[11]. This may be the reason why users place more value on aspects of care that are related to communication, affection and attention[28], such as when the health professional reserves time to listen and respond clearly and openly, understanding that this is a unique situation in the user's life[29].

Also related to treatment by professionals is the need to receive attention, affection and encouragement from professionals; these dimensions are equally related to the satisfaction of feeling cared for. Several studies have analyzed how communication and reflective listening among patients, family members and the multidisciplinary team significantly improve the ability to cope with this final stage of life[30,31]. It is also necessary for professionals to know how to express empathy for the pain and suffering of the person who is going to die. The issue involves synthesizing reflection on one's death and being closer to the death of the actual individual who requires care. In addition, a balance must be reached between overcoming one's fears and being able to confidently approach the pluridimensional reality of someone who knows his end is coming[32,33].

Limitations

With regard to the study's limitations, we consider the possibility that the personal positions of the researchers may have biased the results. To counter this problem, we have in our favor the ultimate motivation of this work—understanding so as to improve rather than merely demonstrate—and we can also note the method of rigorous analysis used in this investigation.

Another limitation is the research design, insofar as our approach did not pull discourse from those who died but instead from the people who accompanied them and interacted with caregivers during the process and who could be the deceased's voices. This situation, which cannot be resolved, must be considered when considering the findings, because the experiences of those who contributed to this study were influenced from the perspective of the grief they were experiencing as well as their personal situations.

CONCLUSION

For the participants in the study, attention was deemed extremely important and necessary in the final phase of disease, as death neared. The quality care was a key factor about which the caregivers and family members spoke with force, firmness,

desperation or satisfaction (depending on their experiences). It was discussed more frequently and intensely than other aspects, which in fact were deemed fundamental, such as the control of symptoms, sedation, socio-healthcare resources, and other key elements of palliative care.

Finally, this study reveals that compassion, understood as "the capacity to open oneself to the reality of suffering and aspire to heal it,"[11] is an indispensable element for participants in the process of believing that good care exists. Closeness, commitment, flexibility, understanding, listening and presence are resources that do not increase health spending; however, according to the testimonials, these attributes make possible a humanized, dignified and, at times, healthy or even good experience of the process of dying and accompanying the dying.

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Conflict of interests

The author do not declare any conflict of interest regarding the investigation, authorship or publication of this article.

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Table 1. Sociodemographic variables of the participants

	Gender		Family relationship				Place of death		
	Male	Female	Spouse	Son /daughter	Father/ mother	Others	Home	Hospital	Primary care center
Discussion groups n = 40	6	34	7	25	1	7	18	19	3
Interviews n = 41	5	36	12	19	2	8	17	23	1

Table 2. Key elements of professional care: Dimensions and sub-dimensions

Dimensions	Sub-dimensions
Technical competence	Control of symptoms
	Continuity of care

Compassion	Effective/affective communication
	Attitudes of kindness and closeness towards the patient and the family
	Generosity and personalized flexibility of care