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Original Article

The process of end-of-life care delivery to the families of elderly patients according to the Family Health Strategy

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Objective: To understand the process of end-of-life care delivery to the families of elderly patients according to a Family Health Strategy (FHS) team, to identify the meanings the team attributes to the experience and to build a theoretical model. Method: Symbolic Interactionism and Grounded Theory were applied. Fourteen professionals working in an FHS located in a country town in the state of São Paulo were interviewed. Results: Through comparative analysis, the core category overcoming challenges to assist the family and the elderly during the dying process was identified, and it was composed of the following sub-processes: Identifying situational problems, Planning a new care strategy, Managing the care and Evaluating the care process. Conclusion: the team faces difficulties to achieve better performance in attending to the biological and emotional needs of families, seeking to ensure dignity to the elderly at the end of their lives and expand access to healthcare.

Descriptors: Family; Aged; Death; Family Health Program; User Embracement; Professional-Family Relations.

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Introduction

Individuals aged 60 and over are considered elderly. In developing countries, they are considered elderly from the age of 60, differently from developed countries, where people are considered to be elderly at the age of 65 and over(1).

This population is highly susceptible to the occurrence of chronic health conditions and countless associated illnesses, many of them in advanced stages. Due to this fact, the elderly and their families are predisposed to an increasing process of vulnerability during the former's final stage of life, without chances of recovering their health(2).

The care provided to people at the end of their lives is a topic considered in the field of palliative care, which is defined as an approach aimed at improving the quality of life of people with terminal illnesses and their families, by way of prevention and relief of pain, early diagnosis, strict assessment and treatment of pain and other physical, psychosocial and spiritual symptoms(3).

Although there are various opinions about the proximity of the fatal prognosis period, the principles of palliative care need to be applied as soon as possible, not only in relation to terminal illnesses, but also concerning chronic conditions, from the diagnosis until the grief process(4).

Particularly in relation to palliative care directed to the elderly, more appropriate and effective healthcare planning is recommended to meet the needs of this population. In that sense, it is important to emphasize the integrative approach among palliative care teams, those providing specialized care to the elderly and those working in primary healthcare(1).

It should be mentioned that, due to the preference of families and elderly patients to receive palliative care at home and the trend of families' reassuming responsibility for the dying, that type of care has also become the duty of primary healthcare services(5).

One of the great strengths of the Family Health Strategy (FHS), which was implemented as a proposal for the reorganization of the Unified Health System (UHS) in the context of primary healthcare, lies in its ability to offer support and strength to the families in situations they may find themselves vulnerable in(6), such as in a situation where the life of one of their family members is threatened by the health conditions.

Both practice and literature(2,4,6) indicate, however, that a large number of professionals still are not able to provide this type of care to the family.

Concerning the care provided in the process of dying at home, it appears that this is a stressful experience for professionals, mainly due to their inability to deal with the families and the lack of availability of technological resources(7).

In addition, the care provided at the end of life in a community healthcare context predisposes professionals to work in a challenging environment, where they are often faced with the requirement to make ethical decisions and with death and the dying process(8).

A study carried out in the Netherlands about the hurdles doctors and nurses have to overcome in order to provide the elderly with care at the end of their lives through home care services showed that these professionals have to face many difficulties to access the needs of the patients and their families(4).

Given the professionals' lack of skills to provide this type of care in primary healthcare services, it is considered important to get to know their experience in relation to the challenge of taking care of families who are experiencing the final stage of life of an elderly family member in the community, since this process also implies care in a context of multiple losses. It is believed that the death of an elderly can also be considered as a loss for the professionals, especially when they maintained a close relationship of emotional nature.

Furthermore, there are only few studies that investigate the interaction between the professionals and the families of people who are dying at home(9).

Based on the above, this study was aimed at: understanding the process of end-of-life care delivery to the families of elderly patients according to an FHS team, identifying the meanings the team attributes to the experience of care delivery to these families and building a theoretical model that represents this experience.

Method

Qualitative research is aimed at offering answers in studies about experiences, behaviors, thoughts, emotions and the performance of healthcare services(10).

Symbolic Interactionism, which is adopted as the theoretical reference, focuses on the nature of interactions, the dynamics of social activities among people, the meanings they attribute to events, the natural environments they live in and the actions they perform(11).

In contrast, Grounded Theory (GT) was defined as a method to guide data collection, organization and analysis and is represented by a set of well-developed and systematically inter-related categories, forming a theoretical structure that explains events such as those related to the relevant experiences of health-disease(10).

This study was carried out in six of the nine FHS healthcare units in Botucatu, a city located in the Mid-West of the state of Sao Paulo.

In Botucatu, each FHS team is responsible for assisting up to 4000 people who live in the area covered by the unit, and is composed of a doctor, a baccalaureate nurse, four to six nursing assistants, four to eight community healthcare workers, a dentist, a dental assistant, an administrative assistant and a general services assistant. All these units are supported by the Family Health Support Center (FHSC) which includes psychologists, social workers, occupational therapists, nutritionists, physical trainers, physiotherapists, pharmacists, acupuncturists, a geriatrician, a gynecologist and obstetrician, a psychiatrist, a pediatrician and a homeopathic physician for assistance in the healthcare unit facility or at the families' homes, periodically and whenever necessary.

The participants in this study were professionals from FHS teams who worked directly with the families of the elderly at the end of their lives (doctors, baccalaureate nurses, nursing assistants and community healthcare workers), wished to participate and had been working in this scenario for at least six months, so that they had acquired a certain period of experience in the work process at FHS and had had more chances of experiencing situations of care delivery to the families of the elderly during the process of death. These participants were personally invited or contacted through telephone by the researcher, when the research objectives and procedures were also explained.

Fourteen professionals were approached and all of them agreed to participate. Twelve of them were women and two were men, aged 23 to 50, two of them being doctors, five baccalaureate nurses, three nursing assistants and four community healthcare workers (CHW). In total, 84 professionals worked in the six healthcare units where the study was conducted. The number of participants, however, was defined by an analysis of the statements collected, through theoretical sampling, until there was a saturation of information, which happened when no new data was revealed and in so far as the identified concepts were better understood(10).

Data were collected from January to October 2009, through photo-elicitation and open interviews, which were carried out at the healthcare units.

Photo-elicitation involves the use of photographs to evoke comments, memories and discussions and is used as one of the techniques to extend the conventional methods of interviews(12). Thus, the photographs were analyzed, but the use of images was a requirement for the professionals to participate in the study. Cameras were loaned to each participant, so that they could take ten photographs that represented the care being provided to the families and the elderly at the end of their lives and were the focus of the recorded interviews, which took between 30 and 80 minutes.

The questions the statements were based on were the following: *Tell me the reason why you chose these images. In what way do they represent, or not, the care provided to the family and to the elderly at the end of their lives? Tell me one situation in which you had the opportunity to provide care to a family in this situation. What was it like to provide care to this family?*

The interviews were fully transcribed and analyzed according to the constant comparative method between categories, seeking similar or different concepts to reveal possible properties and dimensions, in order to develop the theoretical conceptualization(10).

In the first stage of the analysis, named *open coding*, the text of each interview was "open", fragmented into small parts and examined line by line, therefore allowing the identification of codes. Next, the data were compared for similarities and differences and grouped under more abstract concepts, the categories. In the second stage of the analysis, named *axial coding*, the categories were related to their subcategories, with the purpose of generating more accurate and complete explanations about the events. *Selective coding* is the third stage of the analysis and aimed at trying to integrate and refine the theory(10).

Since the objective of the project was the construction of a grounded theory, the results were presented as a set of interrelated concepts through the drafting of a scenario(10) for the presentation of a theoretical model to explain the process.

In this scenario, the categories are presented with the first initial in capital letters. Each category, in turn, consists of subcategories, presented in italics.

It is important to note that approval was obtained from the Institutional Review Board at the University of São Paulo School of Nursing (registration number

725/2008) and that participants signed an Informed Consent Form before the start of data collection(13).

Results

The identified categories and theoretical relationships established enabled the development of an analytical and explanatory process in relation to the actions and interactions that comprised the end-of-life care process provided to families of the elderly. This process was represented by the core category: overcoming challenges to assist the family and the elderly during the dying process.

This process consists of four sub-processes, which represent the symbolic meaning of the experience for the healthcare team. Each identified sub-process was named to constitute the categories: Identifying the situation's problems, Planning a new care strategy, Managing the care and Evaluating the care process.

The integration between categories and their link with the core category permitted the construction of a theoretical model (Figure 1), which represents the healthcare team experience during this specific situation.

The theoretical model makes it possible to visualize how the sub-processes interact, not in a linear manner, but in constant connection throughout the process.

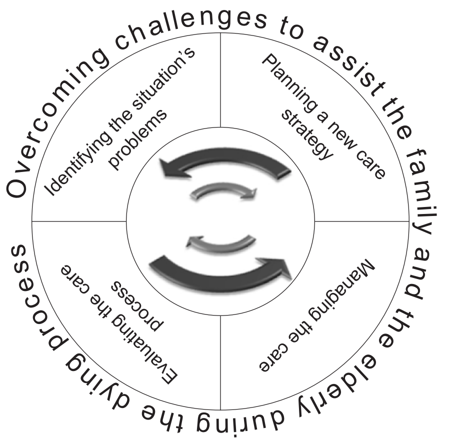

Figure 1 – Diagram representing the theoretical model overcoming the challenges to assist the family and the elderly during the dying process.

The Theoretical Model

Overcoming challenges to assist the family and the elderly during the dying process refers to the action the healthcare team undertakes throughout the experience with the purpose of managing care delivery to the family and protecting the dignity of the elderly in the community at the end of their lives.

Considering the context of extreme poverty, characteristic of peripheral areas where the local ESF teams operate, and the lack of technological resources for care, the research starts with the team Identifying the situation's problems, based on the listing of the aspects they consider to be problematic in their assistance to the family and the elderly. The team analyzes and defines the situation as problematic and therefore stressful, because *it identifies a new condition for care delivery*: the elderly have now reached the end of their lives, and such condition demands special care, different from that previously provided. Furthermore, the professional acknowledges that, in order to fully assist the elderly who are vulnerable and dependent, they will need the support of the families.

Therefore, *recognizing their emotional influence* on the care provided to the families and the elderly at their most vulnerable times, the professionals put themselves in the former's place, feel sorry for their pain and identify themselves with them. The professionals project themselves in the cycle of life and care, which in this case also means facing their own old age and finitude.

The impact of this problem causes intense stress for the professionals because they analyze the situation while *recognizing their own inabilities* to provide care to the elderly at the end of their lives and to their families, making them feel insecure about not knowing how to act and also about the possibility of not being able to provide the best care to the families.

When overcoming challenges related to assisting the family and the elderly during the dying process, however, the professionals analyze the difficulties of the situation and *identify opportunities* that emerge from the link between themselves and the families. This enables the professionals to feel responsible for providing such care.

Despite this fact and the opportunity to honor their commitment to the families, team members realize they can no longer provide the same care as before and feel challenged to develop a new way of working, including the Planning of a new care strategy, aiming to overcome the hurdles and assist the families and the elderly during the dying process.

Overcoming challenges in order to assist the family and the elderly during the dying process, which is marked by a limiting quality of life for the elderly and their family members who experience the process of loss, the professionals start to plan a new form of care delivery, *defining the family as an object of healthcare*. Given the imminence of death, these professionals recognize the family as a system with interrelated parts, which therefore becomes physically and emotionally drained during the care process for an extremely dependent elderly member. In developing a new way to provide care, the team seeks to assist the elderly and their families with their urgent needs during the imminence of death and *prioritize care to the families and the elderly at the end of their lives*. The professionals, fearing the death of the elderly, fight against time to provide the necessary care before death occurs and provide the families, as soon as practicable, with the existing resources and care so that their members do not fall ill themselves.

In planning a new care strategy, the professionals *anticipate the possible connections with other members of their team and with other services*. They consider how to interact with other team members and healthcare services in order to assist the elderly and the families with their needs and expand their access to healthcare actions. They also experience *the interaction with their own self* by reflecting about the meaning of death, the dignity of the human being in old age and the dying process. This helps them organize their thoughts to define death and the dying process and to manage the care provided later.

Aware of the need for a body of self-knowledge that supports their own clinical assessment and their intervention involving the families, the professionals want to enhance their performance in care delivery to the elderly and their families and *seek to acquire skills and knowledge*.

Departing from this planning, the team Manages care through actions and emotions like fear, sadness and sensibility, which make it easier or harder to experience the dying process together with the family and the elderly at the end of their lives, besides overcoming the challenges involved in the experience. During care management, professionals face challenges to assist the families and the elderly in the dying process. When *identifying hurdles to maintain the care flow*, the team notes the lack of skilled human resources and high technology to manage the elderly's symptoms. This raises difficulties to provide the care that is considered appropriate and limits the elderly's access to healthcare actions of greater technological complexity.

During the care management process, professionals may realize that the elderly are badly treated by their families at home and, *recognizing the influence of family barriers on their care*, they believe that this lack of ability by the elderly's family negatively affects the interaction between the team and the family, weakens the established link and makes it harder to share the care.

Overcoming challenges to assist the families and the elderly during the dying process, professionals *manage care with a view to continuity to guarantee a dignified death*, despite their inability to communicate with the families when required to provide information about the elderly's diagnosis. Even so, they seek to overcome such difficulties and protect family decisions, also preparing families for the loss, strengthening the link among their members and assisting during the grieving period after the death of the elderly.

The experience of managing end-of-life care to the families and the elderly in another way is closed off by the Team's evaluation of the care process, depending on how team members feel at the end of the process. The consequences of the interactions and actions undertaken by the team are permeated by feelings of tiredness or professional acknowledgement.

One of the biggest challenges for the professionals, who *feel defeated by death and care*, is to accept the death of their elderly patients, with whom they had built a close emotional bond. In this case, death has a meaning of defeat because they believe that they were not successful in their fight for life and for the health recovery of the elderly.

This combination of intense emotional involvement and professional care prevents the team from establishing professional boundaries with the family. Thus, overcoming challenges to assist the families and the elderly during the dying process also causes stress in the team members, since they intensively dedicate themselves to care activities and perform tasks for the family and the elderly that go beyond the professional scope and, in addition, make continuous efforts to provide the care that is considered ideal.

Based on this, during the evaluation of the care process, the team identifies that it also needs to be assisted and have the opportunity to verbalize fears and anxieties, in order to feel empowered to assist families and the elderly during the dying process.

On the other hand, when the professionals are able to cope with the loss of the elderly, considering it as part of life cycle, they *feel more professionally recognized*. In this context, they recognize the loss of the family, as well as their own, and reconsider the need to assist the grieving family.

This form of care delivery requires the improvement of teamwork, which also constitutes an effective way of dealing with the loss of the elderly and grieving by sharing experiences and feelings amongst the professionals.

When overcoming challenges to assist the families and the elderly during the dying process, professionals find a new meaning for the care and feel motivated to provide the families with the best quality of care, honoring and fulfilling their commitment.

Therefore, the team faces the difficulties that are part of the experience to achieve their best professional performance, attend to the biological and emotional needs of families and seek to provide dignity to the elderly at the end of their lives, thus fully expanding their access to healthcare actions and improving their quality of life, even during the dying process.

Discussion

The need for bonding between family health teams and their clients is part of one of the guidelines that underpin the Strategy in Brazil(14), and this guideline was also strongly present in this study, as an essential condition for care deliver to the needs of families and the elderly during the dying process, thus providing holistic care.

The creation of a context in which professionals and families are able to establish a trust relationship depends on the healthcare team's concept of family(6). The manner in which the team defines family supports and influences the strategies used to maintain the connection and process the care.

The team recognizes that working to honor the existing connections with the families is an opportunity to establish a relationship of mutual trust, especially to overcome what they consider their biggest challenges: the personal inability to reinforce the bad news about the elderly's health condition and the proximity of death.

The act of communicating bad news is a potentially difficult and emotionally draining moment, as the professionals have to deal with patients and families' possible strong reactions to the news and also with their own emotions and fears about their own finitude(15).

The lack of professional training for this task and the refusal to perform it appropriately, however, prevent family members and patients from having one of their rights exercised: the right to information. Being informed about their health status, receiving clear, objective and understandable information about hypothetical and confirmed diagnosis are guidelines of the country's National Humanization Policy(16).

The link built through open communication about the diagnosis and the dying process can allow families to make decisions and more actively participate in the care process, thus becoming a partner of the healthcare team and confirming the shared care.

In the scope of UHS, social control means the active participation of patients and families and is one of the care and organizational principles primary healthcare is based on, besides being an essential condition for the humanization of healthcare(16).

In addition to promoting the exercise of citizenship through social control, open communication with families can make them feel protected. This protection is processed in the essence of the meeting between professionals and families who experience the final stage of one of their members' life and is filled with emotional involvement and the professionals' ability to identify themselves with the families(17).

In this sense, empathy involves understanding the feelings of the person going through a certain situation and also the professional's ability to show them this understanding, being therefore an essential aspect in their mutual interaction, in order to achieve quality in care delivery(18).

The challenge concerning empathy and bonding lies in balancing personal feelings and professional actions, in order not to cross boundaries and to act professionally. The establishment of these boundaries in the interaction helps to support the professionals in the care process, minimizing the impact of stress on them(9).

Also aiming to reduce the impact of professional stress, healthcare team managers and supervisors have a key role to play in creating an environment that allows professionals to discuss the pressures(19) and increase job satisfaction(20).

For this reason, it is essential that team members also receive assistance so that, through the reflections and meanings assigned to their experiences, they overcome challenges and deliver care to families and the elderly during the dying process, thus ensuring the humanization of the care provided.

Final Considerations

Through the analysis of this process, it was identified that providing care to families and the elderly during the dying process means that professionals have to overcome challenges to achieve their best performance, assisting them through open communication, availability and maintenance of the bond established, as well as ensuring dignity to the elderly at the end of their lives and to their families and thus expanding their access to healthcare.

"Overcoming challenges to assist the family and the elderly during the dying process" is a specific theory because, in the ESF context, it permits understanding the process of end-of-life care delivery to families and the elderly at the end of their lives. A formal theory, with a broader scope, can be developed through studies that focus on the care process in multiple contexts, under a variety of conditions.

Although some professionals have presented difficulties to manage their time and take the photographs, it is believed that this was a valuable resource to help them to remember events and evoke strong emotions about their personal and professional experience involving death and the dying, and allowed them to clarify their experiences more profoundly.

The results allow the improvement of knowledge about the dying process in the context of primary healthcare, more specifically, the FHS.

There is an urgent need for professional training in the field of primary healthcare management, in view of the need to go beyond the management of the biological aspects, considering the growing aging population in Brazil – the death theme has to be discussed, since there is high probability that it will happen at home and FHS professionals will be in the community together with the families.

It should also be considered that, in the context of this study, the professionals build and make efforts to maintain a close emotional bond with the families and the elderly and, therefore, when the elderly dies, they also suffer because of the loss and need time and space to deal with their grief.

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