

Provision of Primary Health Care For End-of-Life Older-Aged Patients and Their Families: A Qualitative Study

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Abstract

The purpose of this qualitative study was to understand the primary healthcare professionals' experiences towards the provision of health care for end-of-life older-aged patients and their family members. The theoretical framework used was the Symbolic Interactionism and the research method was the Grounded Theory. Fourteen staff members of a Brazilian health care facility were interviewed. Through comparative data analysis from the interview's contents, a central theme was identified: Committing to Efforts to Provide Care to the Family and Promote Dignified Death to the Elderly. Additionally, five sub-processes were acknowledged: confronting with the meanings given to death; feeling love and compassion for the family; identifying obstacles to keep assistance flow; recognizing the influence of family barriers on care giving and promoting a good death. The healthcare providers' experiences were permeated by strong difficulties. They have taken great effort to get their higher performance in terms of care, when it comes to identify the patient's and family member's supportive needs in order to provide dignity in end-of-life older-aged patient's care, aiming to deliver a more comprehensive health care.

Keywords: Palliative Care; Family; Elderly; Death; Healthcare Professionals-Family Interaction

1. Introduction

End-of-life care is a term used to describe the health care offered to the patients and their families along the process of death and dying, which has variable length of time. The end-of-life period is characterized by a health condition or an inability to develop daily activities, which increases progressively and demands symptom management (Luce, 2010), situation in which most of the elderly are in. The increase of population ageing is a phenomena observed worldwide. From this phenomena, several epidemiological demands emerge, such as the need to consider changes in the diseases' profiles. The meaningful growth of the aging population also requires a critical evaluation of the care being provided to the end-of-life patients in different healthcare settings (Lockett et al., 2014). The older-aged people in end-of-life people are a population requiring appropriate and effective health care planning.

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The adoption of such measures is needed to meet the specific demands of this population. The integration of the palliative care team's members, as well as the adequate prepare of such members and the promotion of professional care, both in care units and homecare assistance, are also required (World Health Organization, 2011; Luckett et al., 2014). It should be pointed out that, since families and patients would rather have end-of-life care provided at their homes (Chen et al., 2014) and the likelihood of family members to take back responsibility for the dying loved ones is an upward trend, such care has been turned into a requirement for primary health assistance (Munday et al., 2009). Therefore, public healthcare professionals must receive specific training to be able to offer interventions that help providing good death at home (Wilson et al., 2013). Thai male nurses have reported that the dignity and privacy, self-assurance, pain control, and dyspnea management were the most important interventions to promote good death (Doorenbos et al., 2013). However, the healthcare providers are not adequately prepared to provide care to the patients' families (Graaff & Francke, 2009; Silva et al., 2011; Malloy et al., 2014), especially in homecare settings (Ward-Griffin et al., 2012), indicating the need to fill the gaps of knowledge concerning family care along the elderly process of dying. To provide care for a patient who will die at home is an exhausting experience for the members of professional staff, especially when they are not prepared to address family member's needs and the technology to provide care is not enough (Valente & Teixeira, 2009; Malloy et al., 2014). Additionally, the provision of end-of-life care in the community involves challenging issues, such as the need to consider the several dimensions involving death and dying (Pereira et al., 2011; Ward-Griffin et al., 2012; Daher, 2013).

A study focusing on the obstacles confronted by Dutch physicians and nurses regarding end-of-life care of older-aged patients has showed that those professionals have faced several difficulties on meeting both patients and family member's needs (Graaff & Francke, 2009). The recommendation for the end-of-life care being redirected around the patients' and their families' needs, as well as the necessity to support them in their own community (World Health Organization, 2011), is in accordance with the Brazilian public health system guideline, that highlights the importance to offer care to the families inside their social and cultural environment. However, in Brazil, it is noted that the families of elderly patients do not recognize the team working in primary health attention as a source of support before the end-of-life experience, perceived as being extremely difficult and suffering-generating situation (Silva, Bouso, Galera, 2010). Probably, it is a problematic that results from the unpreparedness of the primary health attention professional staff, when it comes to deliver this specific kind of care. It is implied to be important to know their experience on providing care to families facing the end-of-life process of an elderly loved one, in their own community, since literature is incipient in relation to researches that focus on interactions between Brazilian primary healthcare professionals and the families of patients who are dying at home. The question we targeted to answer was: What are the experiences lived by the members of the team that provides primary health care for families of older-aged end-of-life patients? The aim of this present study was to explore the experiences toward the provision of primary health care for end-of-life patients in old age.

2 Method

2.1 Study Design

The character of this study's question reflects the interest in understanding processes and changes over time. Therefore, this qualitative study used the Symbolic Interactionism as theoretical framework and the Grounded Theory as research method, in order to understand the primary health care team perspective regarding the process of taking care of families that experience the end-of-life of an elderly loved one. Bearing in mind that this care offered to the family is a dynamic process, it is believed that it can be better understood from an in-depth study of the interactions between all those involved in the experience: the dying elderly patient, the patient's family and the professional team. In this regard, Symbolic Interactionism focuses on the nature of interactions, on the dynamics of social activities among people, on the meanings they give to events, on the natural settings they live at and the actions performed (Charon, 2004). According to this theoretical perspective and to guide and enlighten the path to understanding the process of taking care of end-of-life elderly's families, we decided to use the Grounded Theory method, suitable to guide data collection, organization and analysis, as well as it refers to a set of well-developed and systematically inter-related categories that make up the theory structure to explain phenomena as those associated to the relevant experiences related to illness and health (Strauss & Corbin, 2008).

2.2 Study Setting and Participants

The health care centers are part of the Unified Health System in Brazil (UHS) – a public system created in 1988 by the Brazilian Constitution to cover from primary care services to high complexity procedures in the attempt to ensure full, universal and free service to the country's population as a whole (Ministry of Health, 2010). Fourteen professionals, members of a primary care team with previous experiences with the provision of health care for older age end-of-life patients were interviewed. The study was done in six primary care facilities located at Sao Paulo, Brazil. The professional staff of such settings was composed, at least, by a physician, a nurse, four to six auxiliary nurses, a dentist, an administrative assistant and four to eight community health agents, who are the team members responsible for mediation between the professional staff and the community, in order to facilitate the primary health attention work. However, the study participants were members of the professional team with previous experiences with provision of care for older age end-of-life patients. Doctors, nurses, nurse auxiliary and community healthcare agents, were willing to participate and had been working in that specific setting for at least six months, so that some experience could have been accumulated in situations of family care, end-of-life elderly care and death process. Professionals were invited either personally or through phone calls by the researcher, whom informed them on research objectives and procedures. All fourteen professionals who were invited agreed to participate: twelve females and two males, in the 23-50-year-old range, distributed in two doctors, five nurses, three nurse auxiliaries, and four community health agents. A total of 84 professionals worked at the six health centers where the study was conducted. The number of participants, however, was defined based on the analysis of their testimonials – through theoretical sampling - until data saturation was reached and no new data were disclosed, and as concepts identified were better understood (Strauss & Corbin, 2008).

2.3 Procedures

Data were collected from January to October, 2012. The in-depth interviews were done by the first author of this manuscript. The interviews were done according to the participants' preferences in terms of setting, day and time, being performed in work setting (10) and participants' homes (4). The strategy of photo-elicitation was used, involving the use of photographs to evoke comments, memories and discussions, as it is one of the techniques suitable to extend conventional interviewing methods (Banks, 2009). This strategy turned out to be important for this research, once it contributed to the participants on remembering experienced events and their meanings, stimulating strong emotions about personal and professional experiences regarding to this delicate subject matter that is the end-of-life. Thereby, cameras were made available, so that each participant could collect ten photographs to represent family care as well as end-of-life care to the elderly. The photographic images taken by the participants were the focus of the interviews, which had variable duration, from 30 to 80 minutes each. The triggering questions were: Tell me the reason why you have chosen those images. How do they – or do they not – represent family care and end-of-life care to the elderly? Tell me about one situation when you had the opportunity to provide family care under such circumstances. How was the experience to you? The project proposal was reviewed by the Ethics Committee from the School of Nursing at the University of Sao Paulo (Proceeding 725/2008). Potential participants received information concerning the project and those willing to participate provided their written consent. Standards of confidentiality were clarified and all the participants were made aware that they could withdraw the consent at any time with no adverse consequences (National Health Council, 2012).

2.4 Data analysis

All the interviews were fully transcribed verbatim by the interviewer and other three researchers. A constant comparison of the narrative contents was done to identify the similarities among the experiences and elaborate the preliminary concepts. This strategy allows the identification of possible properties and dimensions, essential to develop the theoretical conceptualization (Strauss & Corbin, 2008). The analysis was conducted in three stages, performed by all the researchers involved in this study. In the first stage – *open coding* – the text from each interview was "opened", fragmented in small excerpts and analyzed line by line to allow code identification. Also in this stage, the data were compared to find similarities and differences, and then grouped under more abstract concepts – the categories. In the second stage – *axial coding* – the categories were related to their subcategories in order to generate more accurate and complete explanation of the phenomena. Finally, in the third stage – *selective coding* – the theory was integrated and refined (Strauss & Corbin, 2008). Given the complexity and the depth reached through Grounded Theory usage, to extract the central category (process) constituted a challenge amid the large amount of data and information compiled.

It was essential to explore various possibilities before electing one central category, advancing and receding, in an attempt to achieve the necessary detachment from the descriptive aspects to get the main analytical idea. At this stage, it was crucial to get support from a more experienced researcher in relation to the method and the interactionism perspective. We also believe that the main researcher's practical experience regarding to the care of end-of-life elderly in the primary health assistance, as well as the accumulated experience in grief and bereavement researches, was vital to contribute and enhance the researcher's ability to conduct intense interviews, as in this study, once the subject stimulated the participants to constantly face their own finiteness. Results present categories description first, but as the objective of Ground Theory is the construction of a theory based on data, a set of inter-related concepts is then presented through a text (Strauss & Corbin, 2008), when categories (sub-processes) are presented in bold type.

2.5 Validity and Rigour

Consistent with Grounded Theory, constant comparative analysis was used to compare the data, identify categories and concepts and direct quotes are provided to illustrate them. To increase the credibility of this research, regular meetings were held with an expert in this method and not involved directly with the search field, so that it was possible to explore fresh perspectives, persistent patterns and differences among the analyzed interviews, allowing the researchers to validate the identified categories. The categories (sub-processes) that composed the analytical process, as well as the central category, were presented to two professionals who participated in the research (one community agent and one nurse), for the purpose of validation and the theory was considered to be representative of the experience lived by these professionals.

3. Results

Categories identification, as well as theoretical associations, allowed the development of an analytical and explanatory process of the actions and interactions that made up the process **COMMITTING TO EFFORTS TO PROVIDE CARE TO THE FAMILY AND PROMOTE DIGNIFIED DEATH TO THE ELDERLY**, with the following sub-processes: confronting with the meanings given to death; feeling love and compassion for the family; identifying obstacles to keep assistance flow; recognizing the influence of family barriers on caregiving and promoting a good death.

Confronting with the Meanings given to Death

Managing end-of-life care is influenced by how professionals see death and dying. Such view will permeate all their actions and interactions during the experience. Their perception moves from seeing death as part of life, and therefore a natural event, to the negative meaning of death and dying, implying losses such as good health and the social role of the elderly. Actually everyone must accept (death), since everyone will die some day...we all know that's the end for everyone...life is just like that (Healthcare Agent – 11) I had a patient (...) who had sudden abdominal pain, was taken to hospital, submitted to surgery, and then went back home with a colostomy, and then, was bed-ridden! Just think, the whole family depended on him for living! (Nurse - 3)

Feeling love and Compassion for the Family

While providing care, professionals identify themselves with the ones they care for, and develop feelings such as love and compassion while interacting with the family. Such feelings are found among people in the same family and reflect deep closeness and emotional links. I liked the old lady and the caregiver so much, I felt so much affection, so much so that I still visit them regularly.... It's like part of the family (Healthcare Agent - 14)

Identifying Obstacles to Keep Assistance Flow

In order to provide care, the team is attentive to identifying the difficulties that hinder the access of both the elderly and their families to the health care system, as well as to regular assistance and consequently, to the continuity of the care process they are responsible for. Providing end-of-life care to the older-age and their families also implies counting on specialized professionals every time necessary procedures require technology that is not available at primary care community centers, such as hard-to-solve symptoms and specific exams.

Professionals at those centers are, then, confronted by complicated situations, since it is not easy to refer patients to reference centers due to delayed assistance, lack of accurate instructions on how to proceed, as well as insufficient availability for the high demand, particularly social assistance, which requires high effort on the team to keep communication among all those services. Something that makes things difficult... maybe (...) is when we have to refer a patient to some specialized center, and there is no availability, we cannot keep assistance flow, we cannot do what should be done... so, I think that whatever depends on us goes smoothly, but if it is not in our hands, then (...) I think things start getting tough... (Nurse - 7) Another aspect that hinders regular assistance flow, and therefore regular assistance by the team, is the difficulty in obtaining resources such as medications that are not available in the health care system, wheelchairs, diapers, specific exams, and bus tickets. System transportation for home visits is not always available either. The lack of resources to provide care to the elderly and their families does many times prevent professionals from providing assistance, which makes them feel helpless, since their job does not depend on personal motivation or efforts in obtaining internal means only, but also on health care system structure. The small things are not so much of a problem... but hospital beds, for instance, that means, "bigger" things, or food staples for the family, expensive antibiotics that must be bought, you see? (...) Last week he (the doctor) could not go for his visit....and I know he really tried hard! It was not that he did not want to go....the health care center car was being used by one of the nurses. (Nurse- 3)

Recognizing the Influence of Family Barriers on Caregiving

The team identifies family difficulties in regard to end-of-life care to the elderly at their home, as well as the burden on family members that are in charge, which entitles them to receive professional care. When I got there on day 1 she (the elderly lady) was like this: on a double bed, lying on a mattress that still had the plastic on... she was lying on that plastic, no sheets! (...) It was quite cold that day, and she...was very cold, I could not get her pulse in her upper or lower limbs...a plastic bottle with orange juice. You know... she looked so old, so down...it was so cold! And she was all crooked... (Nurse - 3) (...) She (a family member) was the only one in charge, and she was overburdened. As time went by I think she started feeling so bad that when we got there she would start talking, saying she had back pain, she could not take it any longer...she kept saying she could not take it any longer. (Nurse Auxiliary- 8)

Promoting a Good Death

Providing good death is also part of providing end-of-life care to the elderly and their families – both in the process of dying and after death, during mourning, and even when personal inabilities arise, such as having bad news in regard to health. All that means acting to meet family needs, to give support to family decisions in regard to the use of resources available to keep on living, or the comfort to the elderly person as to his/her preference for the place to die. It also includes trying to strengthen the ties at the last moments in the life of an elderly person, and act to comfort the family in their mourning after the elderly person dies. Oh, my God... what do I do now? I thought: I must talk to the family... I said: "R.(another professional), please help me". It is always so hard to give such news... we get a little... scared... afraid of saying something and then... scare them... (Doctor – 2) I went on and on working his mind so he would go (die)...so he would make up with one of his sons, they had had a fight (...) and they did make up, and he said good-bye. In his last week he called the whole family. When I got there for the home visit the house was crowded. He reconciled with his son, he left some instructions for his wife...what he wanted done with his car, his clothes...he really thought he was the one to say what he wanted them to do with his things... actually, it was really affectionate... it was like calling everyone for a "great, big hug"... (Doctor - 2) She (a family member) said things like: "Oh, one of the things that makes me sad about his dying is that you are going to stop coming over". Then, we said, "No, we will keep giving you assistance, we have to take care of you too". (Nurse - 7) Such actions are symbols of professionals while COMMITTING TO EFFORTS TO PROVIDE CARE TO THE FAMILY AND PROMOTE DIGNIFIED DEATH TO THE ELDERLY: actions taken by experience-based teams with the purpose to manage family care as well as to preserve the dignity of the elderly at their latest stage in community life.

The team carries out its task in COMMITTING TO EFFORTS TO PROVIDE CARE TO THE FAMILY AND PROMOTE DIGNIFIED DEATH TO THE ELDERLY through actions and emotions – such as fear, sadness, and sensitivity – which make the process of dying within the family environment easier or harder both on the family and on the elderly, as well as to help overcome the challenges that the experience implies. While **confronting with the meanings given to death**, professionals symbolize the death as part of life, but also as a process marked by the fragility and dependency of the elderly. Those beliefs, as well as the feelings professionals nurture for the family, define their actions while providing care.

Therefore, while **feeling love and compassion for the family**, professionals identify themselves with the situations experienced by the families and are influenced in the care they provide and in the emotions that tie them with the family. While providing care, professionals are faced by challenges to comfort the family and the elderly in the process of dying. **Identifying obstacles to keep assistance flow**, the team confirms the lack of specialized human resources as well as of high technology to manage symptoms presented by the elderly. That leads to difficulties in providing the level of care they find appropriate, with a feeling of limiting the access of the elderly to more complex health actions. While COMMITTING TO EFFORTS TO PROVIDE CARE TO THE FAMILY AND PROMOTE DIGNIFIED DEATH TO THE ELDERLY, professionals realize the elderly are poorly cared for by the family at home. And while **recognizing the influence of family barriers on caregiving**, professionals believe that family inaptitude in caring for the elderly hinders the interaction between the team and the family, weakens the ties already established and makes shared care more difficult. Professionals manage care in the attempt to go **promoting a good death** despite the lack of skill in communicating elderly's diagnosis to the family. Even so, professionals try to overcome those difficulties and comforts family decisions to prepare the family for the loss and to strengthen the ties among family members, as well as to provide comfort in the mourning period after death.

4. Discussion

The team faces the difficulties implied in their experience to reach best professional performance, maintaining ties and the interaction with family, harboring the biological and emotional needs of the families and trying to provide dignity to the elderly, thus expanding their full access to healthcare actions and contributing for better living quality standard even in the process of dying. The need to establish ties with the clientele assisted by family health care teams is one of the pillars in the public health care system guidelines in Brazil (Ministry of Health, 2010). That guideline has also been strongly present in the study as a critical component to materialize the harboring of both family's and elderly's needs in the process of dying, thus providing care in completeness. The teams recognize that working on honoring the ties with the family stands for an opportunity to establish trust as well, especially to overcome what is seen as a major challenge: the personal inability to disclose bad news on health condition or the proximity of death. Communicating bad news is a potentially difficult moment, as well as emotionally exhausting, since professionals must deal with patient's and family's reactions – which may be strong – and also with their own emotions and fears before their own finiteness (Lallemand, 2010). Professional lack of preparation for that task, however, and the refusal to perform it appropriately keeps family members and patients from their rights, such as: to be informed on health status; to receive clear, straightforward, understandable information on the hypothetical diagnoses and diagnoses reached are included in the guidelines of the National Policies for the Humanization of Health in Brazil (Ministry of Health, 2006). The ties created through open communication in regard to diagnosis and the process of dying may enable the family to make decisions and to participate more actively in care management, which in its turn may generate a partnership with the team to make shared care possible. Active participation of patients and families is called social control in the public health system in Brazil. Social control is one of the basic assistance and organization principles of primary health care, as well as a crucial element for humanization in health care (Ministry of Health, 2010).

In addition to promoting the nature of citizenship through social control, open communication with the family may make it feel comforted. Such comfort is created in the essence of the encounter between professionals and the family facing the end-of-life experience of one of its members, permeated by the emotional involvement and the ability of professionals' identification with the family (James et al., 2009). This encounter between the professionals and the patient's family happens by means of social interactions, essential to the process of caring for end-of-life elderly's families. Besides, the professionals' ability of introspection, reflection, assigning meaning to the experience and empathy for the families has a positive influence on the overcoming the challenges of family care. In such scenario, empathy involves understanding the feelings of someone experiencing a specific situation, but also professionals' ability to show such understanding – a crucial element in the interaction so that caregiving can reach high quality level (Luce, 2010). The challenge posed by empathy and created ties reside in balancing personal feelings and professional actions so as not to trespass the limits and always act professionally. Those interaction limits support professionals in their caregiving while also minimizing the impact of stress on them (Stajduhar et al., 2011).

Also in the attempt to reduce the impact of professional stress, team managers and supervisors play a key role in creating the atmosphere to allow professionals to discuss pressure situations (Hewinson et al., 2009) and raise satisfaction at the work place (Melo et al., 2011). That explains why it is crucial that the team is also comforted so that through their reflecting and the meanings given to their experience challenges may be overcome and family and elderly comfort can be provided in the process of dying, thus ensuring the humanization of care provided.

5. Final Considerations

The in-depth study regarding the interactions between the dying elderly, the family and the healthcare professionals allows enlighten on the process of family care in the end-of-life circumstance, considering the social activities dynamics between them, the meaning given to the experience by the health team, the context and the actions performed by the team. Process analysis identified that providing care to the elderly and to their families in the process of dying implies that professionals must overcome challenges to reach their best performance, providing comfort both through open communication and availability, and keeping the ties they all have created, offering dignity to the elderly and to their families in the end-of-life care process, and thus expanding their access to health care. COMMITTING TO EFFORTS TO PROVIDE CARE TO THE FAMILY AND PROMOTE DIGNIFIED DEATH TO THE ELDERLY is actually a specific theory since it promotes the understanding of the process of family care and end-of-life care to the elderly in the public service setting in Brazil. A more formal, comprehensive theory can be generated based on studies that focus the caregiving process under multiple setting and a variety of scenarios. The results are a step forward in obtaining better understanding on the process of dying in the primary health care setting.

The need to train professionals to provide specific primary health care is, therefore, urgent. Considering the increase of aging population in Brazil, one must reach beyond caring for the biological aspects – death must be discussed, since home is a very likely location for death to occur. Professionals providing care to the elderly and their families are the ones who will be in the communities and with the families. Yet it must be considered that, in the context of this study, the professional strives to maintain emotional attachment in the interaction with the family and with the dying elderly, and for this reason, when the patient dies, the professional also suffers from the loss and needs time and space to grieve. In addition to assigning a meaning to the experience of providing care in a death and dying context, it is important that the professionals continuously evaluate the caregiving process and the impact of that practice on their own personal life – that is a responsibility that the professionals need to practice, in order to reset strategies concerning their personal grief experience and minimize the suffering impact. Because of this, it is vital that the team leaders and the health system managers offer to the primary health care professionals enough support and understanding while grieving, so they are able to offer a more understanding environment to the families as well, with professionalism, clinical skills, appropriate emotional involvement and empathy for the family needs, ensuring a higher quality care.

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