



Palliative care in the home: perceptions of nurses in the Family Health Strategy*

Cuidados paliativos no domicílio: percepção de enfermeiras da Estratégia Saúde da Família

Cuidados paliativos en el domicilio: percepciones de las enfermeras de la Estrategia de Salud de la Familia

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ABSTRACT

Objective: To understand the perception of nurses from the Family Health Strategy in relation to palliative care in the home. **Methods:** A descriptive, exploratory study with a qualitative approach conducted with nine nurses from the Family Health Strategy of the municipality of Lavras – MG. Semi-structured interviews were conducted and data were subjected to content analysis. **Results:** The various dimensions of care in the home context were identified, along with the performance and limitations of nurses in the care of the patient and his family at end of life. The capacity to establish a bond, by the proximity to people who receive their care, is a remarkable point of the action of these nurses with patients and families in end of life situations. **Conclusion:** The nurses consider the patient and his family as the unit of care, they have the opportunity to share solidarity, experiences and learning, not only from a professional standpoint, but above all, from a human one.

Keywords: Family Health Program; Hospice care; Public health nursing; Home nursing

RESUMO

Objetivo: Compreender a percepção de enfermeiras da Estratégia Saúde da Família com relação aos cuidados paliativos no domicílio. **Métodos:** Estudo descritivo, exploratório, com abordagem qualitativa realizado com nove enfermeiras da Estratégia Saúde da Família do município de Lavras – MG. Foram realizadas entrevistas semiestruturadas e os dados foram submetidos à Análise de Conteúdo. **Resultados:** As várias dimensões do cuidado no contexto domiciliar foram identificadas, bem como a atuação e as limitações das enfermeiras no cuidado do paciente em final de vida e de sua família. A capacidade em estabelecer vínculo, pela proximidade com pessoas que recebem seus cuidados, é um ponto marcante da atuação dessas enfermeiras com pacientes e familiares nas situações de final de vida. **Conclusão:** As enfermeiras ao considerar o paciente e sua família como unidade de cuidado, têm a oportunidade de compartilhar solidariedade, experiências e aprendizados, não só do ponto de vista profissional, mas, sobretudo, humano.

Descritores: Programa Saúde da Família; Cuidados paliativos; Enfermagem em saúde pública; Assistência domiciliar

RESUMEN

Objetivo: Comprender la percepción de enfermeras de la Estrategia Salud de la Familia respecto a los cuidados paliativos en el domicilio. **Métodos:** Estudio descriptivo, exploratorio, con abordaje cualitativo realizado con nueve enfermeras de la Estrategia Salud de la Familia del municipio de Lavras – MG. Se llevaron a cabo entrevistas semi estructuradas y los datos se sometieron al Análisis de Contenido. **Resultados:** Fueron identificadas las diversas dimensiones del cuidado en el contexto domiciliario, así como también la actuación y las limitaciones de las enfermeras en el cuidado del paciente al final de su vida y de su familia. La capacidad para establecer vínculo, por la proximidad con personas que reciben sus cuidados, es un punto marcante de la actuación de esas enfermeras con pacientes y familiares en las situaciones de final de vida. **Conclusión:** Las enfermeras al considerar al paciente y su familia como unidad de cuidado, tienen la oportunidad de compartir solidaridad, experiencias y aprendizajes, no sólo desde el punto de vista profesional, sino también, sobre todo, humano.

Descriptores: Programa de Salud Familiar, Cuidados paliativos; Enfermería en salud pública; Atención domiciliar de salud

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INTRODUCTION

Currently there is a preference on the part of families and patients for the palliative care being dispensed at home, combined with the tendency of changes in society, which leads back to families the responsibility of care for patients who are dying. Thus, care at end of life has become a required competency for the services of primary health care, particularly the proximity to the care provided in the community between the professional teams, patients and families⁽¹⁾.

Knowing nurses' perceptions from the Family Health Strategy (FHS) in relation to palliative care at home, it is believed to be possible to identify the meanings they attach to the process of caring for patients in the final phase of life, as well as possible strategies facilitating or hindering their interaction with the family for care, thus allowing future programs draw to qualify human resources exploited in order to actually provide care to patients and their families.

In this sense, helping individuals with chronic diseases and without curative possibilities, as well as their families in the advanced stage of the disease and end of life lead us to a therapeutic model that has been called Palliative Care.

Palliative care can be defined as active and total care provided to patients whose disease no longer responds to curative treatment. It consists of a differentiated approach that aims at prevention and relief of suffering by means of early identification of appropriate assessment and treatment of pain and other physical symptoms, psychosocial and spiritual needs, promoting the quality of life of patients and their families⁽²⁾.

In Brazil, some standards were subsidizing and encouraging the creation and implementation of services that provide this type of care. Among them, one can cite the Ordinance No. 19 of 03 January 2002, which extends the inclusion of palliative care in instituting the National Health System, the National Assistance Pain and Palliative Care, featuring in article 1, item b statement: "Encourage the organization of health services for the multidisciplinary care of patients with pain and in need of palliative care"^(3,4).

Given this national context, there is a tendency to transfer the patient out of therapeutic healing of the hospital environment to their homes⁽⁵⁾ in order to make death more humane and natural.

Thus, it is essential to train human resources capable of this practice. However, the lack of discrete courses and training related to palliative care in the undergraduate and graduate programs in various areas of health, even in oncology (specialty in which palliative care is most observed) creates a challenging scenario, in which there is plenty to do in terms of research, teaching,

service organization and training of human resources⁽⁵⁻⁷⁾. It is emphasized that the focus of care still falls on the physiological aspects, such as results of strong biomedical culture and therefore the aspects related to family issues and social, emotional and spiritual aspects that are not always perceived as a priority⁽⁸⁾.

Whereas nurses from the Family Health Strategy program must have qualification and differentiated profiles, in order to emphasize their assistance in the interrelationship team/community/family⁽⁹⁾, the opened dialogue approach becomes the key to these professionals dispense the effectively care way, in the presence of a disease that threatens life, if necessary, so in addition to general knowledge about the disease, specific skills to engage and communicate with the patient and family⁽¹⁰⁾.

The aim of this study was to understand the perception of nurses from the Family Health Strategy (FHS) program on home care provided to individuals and their families, within the perspective of Palliative Care.

METHODS

This is a descriptive, exploratory study with a qualitative approach, conducted in Lavras – MG. This city has 17 FHS teams, one nurse per team. The order for the interviews was randomly drawn. The number of participants was settled as a result of the analysis of their statements, since we found the repetition and lack of new data, and a growing understanding of the issues identified, establishing the theoretical saturation of data⁽¹¹⁾.

Nine nurses were interviewed and voluntarily agreed to participate during the period between January and July of 2010; these were aged between 24 and 44 years old; time of ending training of 1 year to 11 years and duration of work for the FHS was from 4 months to 10 years.

At first, the approach was performed with the subjects through telephone calls, on this occasion the project objective was discussed with the participants for obtaining acceptance for participation in the study.

Later, interviews were scheduled for data collection, their statements were about palliative care in the home environment, the interviews were semi-structured, combining open and closed questions using a script, guided by the aim of the research, addressing aspects of patient care and family in home context.

The questions which guided the research were:

1st. Have you ever had the experience of caring for a patient at the end of his/her life as a FHS nurse?

2nd. If yes: Tell me about that experience. What were your care actions in this situation? What were the main patient's needs met? What do you think that could be improved in the care of this patient?

3rd. If not: If you had a patient at the end of his/her life in your care, what would be your care actions in this situation?

4th. For both cases: How was your training toward death and end of life care? What is your role as a nurse in palliative care? What is your opinion about taking the patient home to die?

The interviews were scheduled and conducted in units of the Family Health Strategy where each of the participants worked. We carried out the recording of the interview for later transcription and discourse analysis. It is emphasized that participation was voluntary and, before each interview, the purpose of the research was explained. After that, we asked the interviewee to read and sign the Consent Form. The research project was approved by the Municipal Health Department of the city and by the Ethics Committee on Human Research of the University Center of Lavras – UNILAVRAS (CAAE – 0025.0.189.000-09).

The data were subjected to content analysis, using the technique of thematic analysis, which requires dismembering the text into thematic units, based on the study objectives. Thematic analysis' aim is to discover the meaning units that make up a communication, whose presence or frequency mean something to the analytical objective pursued⁽¹²⁾.

The discourses from the interviewees were presented by a code composed by the word "Nurse" followed by a number from 1 to 9, determined by the sequence of interviews, to guarantee their anonymity.

RESULTS

Based on the discourse analysis, it was possible to identify the following categories:

Decision of taking the patient to their home

Overall, the decision to take the patient to die at home is made by a physician who have treated the patient during hospitalization. However, the family and the patient, when conscious, may question the doctor's decision, still, the interviewees stated that the situation of patients in end of their life should not remain in hospitals.

"In therapy unit is the physician, who is treating him [patient] in the hospital, who will decide" (Nurse 4).

According to the interviewees, in order for the family to take the patient in the end of his/her life home, they need a certain structure for care and also accept the inevitability condition of death of the patient. For nurses, it is beneficial to the patient to remain with their family at home at the end of life, but they point out that it is difficult for the family to be responsible for the care the patient needs.

"You follow the family, if they have accepted and have structure to keep the patient at home, it is better to stay at home" (Nurse 3).

Patient's wishes at the end of life

The agreement of the family to take the patient home is mainly guided by his/her desire to die at home. Therefore, when the physician proposes to transfer him/her home, this is perceived as a possibility of doing a patient's wish before his death.

"Her wish [the patient's] was not to stay in the hospital in any way" (Nurse 3).

Another aspect mentioned, concerns the willingness of patients to receive or not receive medications to treat severe pain which in general is done with the use of opioids. The interviewees pointed out it is important to respect the patient's wishes when he/she refuses these medications because they cause sedation, considering the patient's desire to stay sane in the last moments of his/her life.

"She [patient] did not take strong pain medication ... did not want strong medication, afraid this would make her sedated" (Nurse 3).

Limitations and Role of the Family Health Strategy program

The interviewees highlighted that the ideology of the FHS is not to offer a contribution to home care to patients and their families. The support they offer families is important, however, nurses emphasized that family members cannot leave the whole patient care under the responsibility of the team, because they are unable to provide this type of care due to the high demand and objectives of FHS. In this sense, the role of the FHS program, in the perspective of the nurses participating in the study, is to give support to the family, enabling them to provide the care the patient needs.

"... there's no way we can be there [at home] all the time" (Nurse 7).

"We help bathing the patient, we take a look at the medicines he/she is supposed to take, if there is any dressing, we can do that, and we also provide guidance for all the rest of the day and night" (Nurse 5).

Nevertheless, there was a big concern of nurses with respect to the staff time available to provide adequate assistance to the patient and his/her family. There are several limitations of the FHS program, such as: lack of time and the professionals working hours of the FHS, ie on weekends and holidays the patient and family have no one to give them any kind of support.

"We do our part within our means, but we are limited because we are not here 24 hours. The FHS only works eight hours on weekdays. So during weekend, holidays, nights, we are not here" (Nurse 5).

Family care

Nurses considered the equivalent importance of care to both patient and their family. The family plays a fundamental role in patient care in the final stages of life and, accordingly, must be prepared to care for him/her in the absence of FHS professionals. For this reason, it is necessary that professionals work for families to be structured during the entire process of end of life of the patient.

"Family care and support is as important as the patient's care and support" (Nurse 1).

Family involvement begins with home visits and, from that moment, the nurses know the environment, observe the reactions of each individual and investigate the needs of the patient and family. Thus, they find themselves in a better position to offer care that meets the real needs of the family.

"Getting involved with the family, how the family is doing, we try to give an emotional support, involving the family, focusing on the whole situation" (Nurse 2).

Interviewees highlighted the importance of explaining the real situation to the relatives of the patient. Therefore, staff provides information about the stage of the disease, solves doubts and tries to anticipate for the family what will happen to the patient, so that they can be prepared for death.

"I try to establish dialogue, always guiding them about what is happening with the patient, explaining what might happen, preparing the family for the future" (Nurse 6).

Bond with the patient and family

Based on interviews, it was noted that patients on their end of life require a service equivalent to that given to an individual who has the possibility of cure. Thus, the nurses consider respect, attention and care essential feelings provided to the patient at the end of life and their family. Through them, professionals demonstrate to their patients that they are important and that they are human beings, ie, provide emotional care to these people.

"It is not because he [patient] is there at the end of life I'll do it anyway. I care for him as I would care for any other person, taking all possible care" (Nurse 2).

"Talking to her [patient] because she had no one to talk to and she loved to tell stories. So, besides the dressing, we also offer emotional support to her. Chatted, gave her attention" (Nurse 9).

Through home visits, nurses are able to establish a bond with the patient and family, ie the interaction between patient/family and nurse starts based on conversations established between them. This link allows the nurse to feel safe to detect and to meet the needs of the patient at the end of life and family and consequently care becomes individualized.

"It has this good side of the bond, the side that we create an intimacy with the patient and family" (Nurse 4).

Working in a multidisciplinary team

The content of the interviews highlighted the importance of the integralization of actions of the various professionals of the multidisciplinary team: nurse, physician, psychologist, physiotherapist, dietician, community health worker, nurse technician and nursing assistant, so that the patient and his/her family can keep the end of life care at home.

"We always have to be working in teams, because alone we do not get anywhere" (Nurse 5).

Interviewees also emphasized that the nurse and the physician are the professionals who have greater contact with the patient and his/her family, and also the important role of the dietitian, physiotherapist, psychologist, agents, nurses technicians and nursing assistants.

"Nurses and physician have more contact with the patient and family. The psychologist is not even on the team, he/she is from the Center for Support of Family Health. But the person who deals with this situation directly is me, the nurse and the physician, we are the ones who talk to the family" (Nurse 4).

The psychologist is identified as important in the situation of a patient at end of life, however, not all FHS programs have that professional, so nurses usually take this responsibility to emotionally care for the patient within their means.

"... we do not have a psychologist working with us" (Nurse 8).

"So we do the way we can, in fact, the ideal would be for all teams to have a psychologist because he is the one who knows all the cognitive and emotional approaches for the patient" (Nurse 1).

Network support

When the patient remains at home at the end of life, in addition to family support, he/she also has the opportunity to receive support from their extended family and friends, so he/she can face the inevitability of death. Besides these people, the patient and family can also count on the support of the FHS team, when there is some complication with the patient.

"Her friends talked to her and tried to get her [patient] to accept the situation" (Nurse 3).

The interviewees also indicated the importance of religiosity and participation of members of the religious community of the patient so he/she feels cared for and realize they are not alone during the dying process.

"... not only the Catholic religion, there were people who came, people who went to their houses, such as Jehovah's Witness ..." (Nurse 3).

In the situation where the patient has no family support in care and/or live alone, neighbors and friends are the people who help them in difficult times. Under these conditions, the orientations regarding patient

care are passed on to people who are with him/her at the time of visit, such as neighbors, friends, nephews, among others.

“The patient stayed home because of a neighbor, a friend” (Nurse 5).

Academic Background related to care at the end of life

Interviewees pointed out that, although the subject of death has been discussed during their academic life, the largest approach is still in the healing area, most of the training focuses on how to restore the patient's health. Nurses reported that they could learn about the importance of respect and individualized care in end of life situations, however, reported that they had little contact with such patients during their academic training, emphasizing the importance of experiential component, and not just theoretical, in end of life situations.

“We do not have practical training, when practice happens, then we really start to learn” (Nurse 4).

“Experience, experience we gain according to the situations in which we live in, as we live we learn” (Nurse 3).

DISCUSSION

The data showed that, in general, the decision to take the patient to die at home is made by a physician who have been taking care of him/her during hospitalization. Moreover, after the clinical assessment of the patient in the hospital service, at hospital discharge, family members rarely neither receive clear information about the disease, orientation and/or support to provide home care nor receive reference on a support service to continue the treatment after hospital discharge⁽¹³⁾.

The care for the patient during the process of dying at home is a difficult and stressful experience for nurses, especially due to the lack of ability to deal with families and the lack of availability of technological resources⁽¹⁴⁾. According to the nurses, it is not the role of FHS program to provide the same technological resources of a hospital or home care service. Nonetheless, the staff, especially nurses, should aim to meet the demands of patients in end of life situation. Aspects such as the promotion of comfort and improved quality of life are paramount to ensure the dignity and autonomy of the patient, involving the family in care.

One of the aspects proposed by palliative care is to control symptoms and, among them, the pain. For pain control, medications such as opioids may be used. However, data show some fear on the part of patients using opioids because of its sedative effect. Accordingly, nurses emphasized the importance of respecting the patient's wishes to receive or not these medications due to sedation they cause. Thus, the more we respect

patient autonomy and participation of family members in the discussion of the evolution of the clinical and therapeutic procedures, the greater the success of the humanization of care provided to patients at end of life⁽¹⁵⁾.

The FHS assistance to the patient and their family begins based on coexistence with these people. As a result, the nurses, with their team, organize space household where care will be developed⁽¹⁴⁾. However, for the patient to receive end of life care at home, it is necessary that the family is also responsible for such care.

The multidisciplinary work of FHS also assumes critical importance for addressing family health, particularly in home care, which involves professionals, patients and their families. Nevertheless, many professionals perform their practices so individualized and often viewing the family as a mere recipient and provider of information⁽¹⁶⁾.

The difficulties faced by relatives of patients outside the therapeutic possibilities at home may be related to the lack of information about the disease and prognosis, with the financial situation, the conflict between feelings of those who care and who is cared for, with lack of knowledge about the disease itself, among others. These difficulties may become more intense or minimized through basic information about care⁽¹⁷⁾. The discourses of nurses resemble that described in the literature, that is, they also believe that the difficulties faced by families could be lower, if they knew in advance the possible situations that can occur with the patient, and how the caregiver can act for each one.

The crying and the voice of the patient's relatives in end of life situations and feelings are externalized forms of relief, which promote a sense of relief⁽¹⁸⁾. Nurses also believe that comfort and support to the family may be offered through a good conversation, dialogues and listening. Thus, the family feels safer and more comfortable in opening up to the professional.

Generally, nurses have contact with the theoretical basis for the care of patients at end of life, though, these professionals demonstrate low assimilation of theoretical knowledge to professional practice. The actions of most of these professionals are the result of their experiences acquired in the daily practice of work⁽¹⁹⁾. This shows that the curriculum of undergraduate nursing colleges has subsidized qualitatively the formation of a knowledge oriented care in situations of end of life and death.

Thus, it is a challenge to focus on the logic of FHS care production, as it is reflected in the work oriented to the problems, needs and quality of life of users⁽²⁰⁾. These actions, besides contemplating the necessary procedures, such as dressing and probing, also seek to integrate human relationships, the bond and care.

FINAL CONSIDERATIONS

This study allowed us to understand nurses' perceptions of FHS program in home care to the person who needs palliative care and their families. Through these perceptions, unveiled categories that could subsidize the effective care of patients and their families during the dying process in the home context.

The data showed that the decision to take the patient to die at home is made by the physician who takes care of the patient during hospitalization, evidencing the low participation of patients and their families with regard to the process of decision

making related to actions with patients outside of therapeutic healing.

In this study, we understand that the ability to establish connection by proximity to people receiving care, is a remarkable point of the performance of FHS nurse with patients at the end of life and their families. By proximity to the family, the nurse sees new opportunities and learn new ways to take care of health care, based on their professional practice.

When considering the patient and family as a unit of care, nurses have the opportunity to share solidarity, experiences and learning, not only from the professional point of view but, above all, from the human point of view.

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