

## PARTICIPATION OF NURSES IN PALLIATIVE HOME CARE

### PARTICIPAÇÃO DA ENFERMEIRA NOS CUIDADOS PALIATIVOS DOMICILIARES

### PARTICIPACIÓN DE LAS ENFERMERAS EN ATENCIÓN DOMICILIARIA PALIATIVA

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## ABSTRACT

The research aimed to describe the home palliative care provided the nurse; identify existing interrelationships between nurse and patient in the family home palliative care; characterize the significant moments of nurse participation in home hospice care. This was a qualitative research with descriptive exploratory approach. Data were collected through a semi-structured interview, conducted with eleven nurses that home palliative care and analyzed according to Bardin content analysis. The results showed that the participation of nurses in palliative care occurs through the identification of needs and recognition of the context in which the patient is inserted, realization of nursing care by creating links with the patient and family, and the experience of meanings moments in making the care. It is concluded that the presence of the nurse in this modality of care is fundamental and can contribute to the structuring of this care in the Brazilian Unified Health System.

**Keywords:** Palliative Care; Home Nursing; Nursing.

## RESUMO

A pesquisa teve como objetivos descrever os cuidados paliativos domiciliares realizados pela enfermeira; identificar as inter-relações existentes entre enfermeira, família e paciente nos cuidados paliativos domiciliares; e caracterizar os momentos significativos da participação da enfermeira nos cuidados paliativos domiciliares. Tratou-se de pesquisa qualitativa com abordagem descritiva exploratória. Os dados foram coletados por meio de uma entrevista semiestruturada, realizada com 11 enfermeiras que realizam cuidados paliativos domiciliares e analisados segundo análise de conteúdo de Bardin. Os resultados demonstraram que a participação das enfermeiras nos cuidados paliativos ocorre por meio da identificação das necessidades e reconhecimento do contexto no qual paciente está inserido, realização da assistência de enfermagem com a criação de vínculos com o paciente e família e a vivência de momentos significativos na realização do cuidado. Concluiu-se que a presença do enfermeiro nessa modalidade de cuidado é fundamental, podendo contribuir para a estruturação desse cuidado no Sistema Único de Saúde do Brasil.

**Palavras-chave:** Cuidados Paliativos; Assistência Domiciliar; Enfermagem.

## RESUMEN

La presente investigación tuvo como objetivo describir los cuidados paliativos domiciliarios llevados a cabo por enfermeras; identificar las relaciones existentes entre enfermeras, familias y pacientes en tales cuidados paliativos y caracterizar los momentos significativos de la participación de la enfermera en dichos cuidados. Se trata de una investigación cualitativa con enfoque exploratorio descriptivo. Los datos fueron recogidos a través de una entrevista semiestructurada a once enfermeras que realizan cuidados paliativos domiciliarios y fueron analizados según el análisis de contenido de Bardin. Los resultados mostraron que la participación de las enfermeras en la atención paliativa se produce a través de la identificación de las necesidades y el reconocimiento del contexto en el que se inserta el paciente, que los cuidados de enfermería se llevan a cabo mediante la creación de vínculos con el paciente y la familia, y la vivencia de momentos significativos cuando se realizan dichos cuidados. Llegamos a la conclusión que la presencia de las enfermeras en esta modalidad de atención es esencial y que podría contribuir a estructurar este tipo de atención en el Sistema Único de Salud de Brasil.

**Palabras clave:** Cuidados Paliativos; Atención Domiciliar; de Salud; Enfermería.

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## INTRODUCTION

As a possibility to provide adequate care to the population in the process of aging and development of diseases directly affecting the quality of life, there are palliative care aimed at provide quality of life for patients and their families through the prevention and relief of suffering, and treatment of pain, and other physical, psychosocial and spiritual signs and symptoms that the patient may have.<sup>1</sup>

Palliative care is considered as a philosophy of caring, carried out on patients with chronic degenerative diseases or non-communicable diseases, whose focus is to provide the patient and his/her family with a better quality of life, and the home becomes an environment favorable for this care. This way of caring is guided by the principles of bioethics and seeks to preserve the people's autonomy over their life and their death.<sup>2</sup>

In this sense, the importance of understanding the home context is highlighted, as the scenario that encompasses the peculiarities and the dynamics of each family, and includes factors that influence the life of these people, such as income, beliefs, customs, values, knowledge, and practices that guide their actions.<sup>3</sup>

By understanding the home environment, nurses can develop knowledge and strategies that contribute to the development of their care practice, helping the patient to accept the diagnosis and living with the disease, developing integral care for the patient, and family members to uncertainties arising from the disease.

By the different approaches researched in palliative care, the relevance of this research is justified by the existence of few studies and scientific publications, especially national studies, in the area of home palliative care, especially regarding the perception and participation of the nurse inserted in this context. Thus, this study aimed to describe the home palliative care performed by the nurse; to identify the interrelationships between nurse, family, and patient in home palliative care; and to characterize the significant moments of the nurse's participation in home palliative care.

## METHODOLOGY

This study is a qualitative research with a descriptive-exploratory approach. Eleven semi-structured interviews were conducted with nurses who develop home palliative care: six nurses residing in the city of Guarapuava, three in Campo Mourão and two in Curitiba. Although the number of nurses working in home palliative care is greater than the sample of this research, it was not possible to interview them because of lack of authorization from the institutions in which they worked or because of refusal to participate in the study. The interviews took place from July 2013 to January 2014. The inclusion criteria were to be a professional graduate in nursing and

to be working in the modality of home palliative care. The interviews had an average duration of 30 minutes and recorded with the use of a digital recorder, later heard and transcribed in full for reading and data analysis.

The obtained data were grouped and analyzed through the technique of content analysis, understood as a set of techniques of analysis of the communications, whose purpose is to obtain systematic procedures and objectives of description of the content, allowing the induction of information about the categories.<sup>4</sup>

The research was submitted to the Research Ethics Committee of the Health Sciences Sector of the Federal University of Paraná. The project was registered in the National System of Information on Ethics in Research Involving Human Beings (SIS-NEP), respecting the norms of Resolution of the National Health Council 466/12. Participants were informed about the research objectives, benefits, their anonymity and the identity preserved. Also, they were informed about the absence of risk, and the participants after receiving the information should sign the Informed Consent Form (TCLE) if they accepted to participate. The project was approved under opinion 202.732 of February 21, 2013.

## RESULTS

The data obtained from the participants' statements were grouped into the following thematic categories: The nurse before the home palliative care; The inter-relationships between patient, family and nurse care; The participation of the nurse in significant moments of home palliative care.

### THE NURSE BEFORE THE HOME PALLIATIVE HEALTH CARE

This category has two subcategories called: "Recognizing the context of life and the needs of the patient and family" and "The nurse performing home palliative care with the interdisciplinary team".

In the sub-category "Recognizing the context of life and the needs of the patient and the family", the research participants reported that, when they perform palliative care at home, they first recognize the environment in which they are going to provide the care, identifying their strengths and weaknesses. Before the visit, the nurse reports on the patient's pathology, treatments performed and medications used through the patient's chart when he is referred to this type of direct care from the hospital or talking with the patient's family members.

*[...] first, I try to know about the patient through medical records, history of his illness, before going to the home. I do not like to go blind in a house (Nurse 02).*

*[...] I want always to be informed about who knows the house and the patient better, so I look for the caregiver when possible. When I do not find him, I have already spoken to the nearest neighbor to give me information about the patient and the family (Nurse 03).*

*[...] in the visit, I try to identify the climate between the family and the patient, the conditions of this patient stay at home, ask questions about who takes care of him (Nurse 05).*

Thus, the care provided will be adapted to the patient's reality. The nurse uses this moment to begin her approach with the family and with the patient, according to the following reports:

*[...] most of the time, I am very discreet, and I do not ask about these conditions, I do this analysis of the environment through observation (Nurse 01).*

*[...] I always ask if the house is rented or own, what destination they give to the trash, who works in the house or if the patient receives some kind of benefit [...] (Nurse 04).*

*[...] who lives in the house? How many people? I usually observe everything: the looks between the relatives, the place where the patient is, the bed, the sofa, the bedroom, where he bathes and does his needs, especially when he is already weakened [...] (Nurse 08).*

Another aspect considered relevant when recognizing the home environment was the presence of the family member who cares for the patient, known as an informal caregiver.

*[...] when I arrive at the patient's home, I ask who cares for him and receive many answers: children, wives, nephews (Nurse 05).*

*[...] not always the caregiver is a relative, sometimes they are neighbors or known people who do not know how to talk about the patient and his health condition (Nurse 03).*

*[...] I identify who in the family cares for the patient, I think this is one of the most important steps in the care because it is the link (Nurse 10).*

By identifying the patient's human needs at home, the nurse can make a diagnosis, that is, identify the problems, tracing their care planning, which must be re-evaluated continuously according to the patient's evolution. Within the context of

palliative care, there are biological, psychological, social and spiritual needs, following the philosophy of this modality of care.

*[...] carrying out the care, identifying the needs knowing what that person needs, what medicine to take, if they use any equipment [...] (Nurse 05).*

*[...] it is necessary to identify the physical, psychological, social, spiritual and affective needs so they can be attended in their integrity, giving comfort to the patient (Nurse 06).*

*[...] I raise the physiological needs and the others also to be able to direct my care, I have to have a planning where I start and where I want to arrive, it does not matter much the patient's illness... (Nurse 09).*

The second subcategory of this thematic is called "The nurse performing home palliative care with the interdisciplinary team".

It is fundamental the diagnosis of the needs of the patient and the family to perform the nursing care, as seen in the previous item. The home palliative care is complex since this care is not limited to the execution of techniques, requiring the professional to perform an integral, humanizing and shared the action with a team assisting in this execution of the care, called an interdisciplinary team. It is noteworthy that this team's objectives is to develop the role of educating in health and providing care in an integral way, providing an improvement in the quality of life of the patient and family.

*[...] I do not do the care alone, I need a team, in which everyone speaks the same language with the patient, it's a lot of work for a professional only [...] (Nurse 08).*

*[...] exchanging ideas as the other members of the interdisciplinary team is very good, as we take care of the patient jointly (Nurse 09).*

*[...] the nurse ends up being one of the professionals who stays longer in the home, so he can understand the context in which the family and the patient are inserted, passing on the information to the other professionals of the team (Nurse 10).*

## THE INTER-RELATIONSHIPS OF PATIENT, FAMILY AND NURSE CARE

This category was built by the relationship established between the patient, the family, and the nurse care. In this

theme, two subcategories denominated “The approach of the nurse with the patient and the family” and “The creation of bond in the relationship of care” emerged.

The subcategory “The approach of the nurse with the patient and the family” explains that the approach of the nurse in the home allows knowing the relationships between the patient and his family, enabling to evaluate their real needs in an integral and humanized way. After all, it is up to the professional nurse, who lives the reality of the patient, to recover their self-esteem, to provide comfort, pain relief, and individuality.

*[...] the approach is continuous, I am always approaching the events of the family and the patient, they tell me all the news that occurs, if I stay without visiting for a week, as soon as I arrive, they always talk about the news [...]* (Nurse 01).

*[...] in the terminal phase, it is almost always the family that tells how the pain is, that is, the patient's complaints* (Nurse 06).

*[...] I try to approach the situation they are experiencing to understand what they are feeling. The approach makes me better able to identify problems and help this family cope with difficult situations* (Nurse 08).

*[...] the moment of the visit is when I approach the patient, the family, the problems, the needs, the feelings and anxieties that surround that house, for me this is the time to approach* (Nurse 09).

The approach of the nurse with the family and the patient enables their inclusion in the care plan that must be adapted to meet the needs and by the conditions and the family dynamics.

*[...] Sometimes, I plan in a certain way, when I get closer to the familiar, I realize that I have to redo my planning because it can not be deployed to that reality I envision* (Nurse 04).

*[...] I already did a lot of planning, and I had to change according to the needs of each family, the closer I got to them, the more I noticed and changed my actions* (Nurse 07).

In the subcategory “The creation of bond in the relationship of care”, it is explicit that bonding is a primordial element in care, it is something to be desired by the health team.

The link is the basis for achieving greater impact in the work process, especially when it comes to preventive measures for chronic diseases and noncommunicable diseases.

*[...] I talk a lot with my patients, but sometimes they do not have the conditions for a conversation, but we understand each other through gestures [...] a little girl draws for me...* (Nurse 07).

*[...] the relationship is harmonious when there is a bond because they trust me and perform the care more easily, everything I say seems to be absolute truth. See responsibility* (Nurse 08).

*[...] for them to trust us, it is not from one day to the next, several visits are necessary, it is like a courtship, it needs coexistence* (Nurse 11).

## NURSING PARTICIPATION IN SIGNIFICANT MOMENTS OF HOME PALLIATIVE CARE

This category shows that, given the adversities experienced at home, some moments are considered significant, highlighting the moments related to the death process in this research, coping with death by the patient and family and support after death.

*[...] there is no way to escape, we are all going to die!!! And I speak of death when the family asks me [...] I do not really know the exact time to talk about death, but I tell everything I know about the patient's prognosis* (Nurse 06).

*[...] the acceptance of death by the family is a very difficult time, there are revolts and questions about how nothing can be done with so many resources* (Nurse 07).

Death is much more than a biological process, it is a social construction, and can be lived in different ways according to the meanings attributed to it, being influenced by the sociocultural context. It is important to conceive of death as a process and not as an end, so the patient in his final moment must be heard, understood, respected.

*[...] I realize that when the patient chose to be at home, he better solves the issues of death to resolve family conflicts and to do the things he liked, eating food, shower, receiving visitors [...]* (Nurse 04).

*[...] it is necessary to speak to the family about death, but it is difficult, no one is prepared to talk about it, we are not prepared for it, I seek [...] to cling to my religion to speak (Nurse 05).*

The research reports indicate that before they are professional nurses, they are human beings with feelings. Death is considered a significant moment in the professional trajectory of palliative care because it is tied to the feeling of impotence.

*[...] I experienced a moment in my professional trajectory in which the patient's daughter looked at me saying you were here, and he died anyways (Nurse 04).*

*[...] I am very sorry when I lose a patient, I cry with the family, I am sad, in short, we create bonds with them, and we are human too.(Nurse 06).*

Death is feared by all, no one is prepared to face it. However, in cases where patients progress rapidly go into the terminal phase, it becomes imperative to be truthful about the patient's progress and the possibility of dying. The nurse must face the facts and explain to the family what is happening to be able to pass safety and credibility. At some point, it is necessary to talk about death, after all, this family relies on the work of the nurse with whom it has established a bond.

*[...] Dona Maria asked me: "Nurse, will he soon die?" And I said, "The disease is well advanced, and he is weakened, I believe so." On Sunday, she called me and said, "As you said, he's gone..." (Nurse 06).*

*[...] I speak of death when the family wants to speak and when the patient dies, I go there, I accompany the family, I give the necessary guidelines, and I go to the funeral [...]. (Nurse 04).*

*[...] I realize that people at home can even speak about their own death (Nurse 02).*

*[...] once the patient wanted to say goodbye to his children and asked me to get them together, but do not tell me what. It was exciting, he talked to them all, said good-bye and died (Nurse 09).*

Another moment considered significant in the accomplishment of home palliative care is the support for the family member after the death of the patient.

The family is remembered and also assisted after the death of the patient. One of the essential functions of palliative care

is the comprehensive care of family caregivers. From diagnosis to the onset of illness and death, the nurse is close to the family, involving both parties and bonding, which can not be interrupted abruptly after the death of the patient.

*[...] when the patient goes, the family stays. It is fundamental not to abandon them, I visit the family, I call to know how they are [...]. (Nurse 07).*

*[...] there is some houses where the patient has passed away for over a year and I continue going there to visit the wife, to know how she is, we create a relationship of friendship, of affection (Nurse 09).*

*[...] I think it is important to continue care at the moment of mourning, which is so delicate for the family, I can do something for this family, like listening to it, giving it strength, encouraging it to follow their life (Nurse 10).*

*[...] when we meet again the family member, we remember the moments we witnessed together, we are sad, we cry, but we also talk about good things, about everything we did at home (Nurse 10).*

*[...] there is a man whose wife has passed away two years ago, and he does not forget us, wherever he is, he comes, talks and thanks for everything we have done for him (Nurse 11).*

## DISCUSSION

This study verified the participation of nurses in home palliative care by identifying the needs and recognition of the context in which the patient and the family are inserted, performing nursing care, creating relationships between patient, family and nurse and experiencing significant moments in the accomplishment of the care.

In this sense, a home visit is a form of home health care, providing subsidies for the implementation of the other concepts of this health care model. Through the visit, the professionals capture the reality of the individuals assisted, recognizing their problems and their health needs.<sup>5</sup>

Another aspect considered relevant in the research when recognizing the home environment was the presence of the family member who cares for the patient, known as an informal caregiver, being a function assumed by family members, friends, neighbors or other groups of people in the provision of care without economic remuneration by the act of caring.<sup>6</sup>

Therefore, the caregiver is an important character to ensure the success of home care with a fundamental role in the provi-



sion of care, since it is who assumes and guarantees the maintenance of the necessary assistance to the patient at home.

When the responsibility for nursing care is transferred to the family, it is up to the nurse to teach the family how to take care of the patient for the accomplishment of home care, respecting the capacity of understanding and the action of the caregivers.<sup>7</sup>

The home care team that knows the family routine enhances the care actions and has the possibility of creating links of mutual support, exchanging and understanding of fragilities and potentialities, visualizing the scenario and integrating the actions for patient and family.<sup>8</sup>

In this process of conducting home palliative care, the relationships between family, patient, and nurse were evidenced. The family is referred as a unit of care, showing social, spiritual, physical and psychological demands in the care process of its sick family member<sup>1</sup>, encompassing a set of values, beliefs, knowledge, and practices that guide health promotion, prevention and treatment, being a health system for its members.<sup>9</sup>

Again, the home visit is highlighted as a mechanism for creating bonds, represented as a state of 'respect' and 'trust' conquered by professionals with the users and built by coexistence and constant contact.<sup>10</sup>

Facing the adversities experienced at home, some moments are considered significant, especially in this research, the moments related to the death process, the coping of death by the patient and family and the support after death.

Understanding death as a natural process of life is not an easy task. Spiritual belief in this difficult moment is perhaps the only tool of relief from the suffering of ultimate detachment from life.<sup>11</sup>

In this sense, caring for the patient at the end of life sensitively and integrally means expanding our understanding of the human being beyond the Cartesian model, and for all actions in palliative care, we must seek an expanded view of human complexity.<sup>12</sup> The professional must be able "to respond to human suffering in the physical, psychological, social and spiritual dimensions by experiencing frailty in the process of dying at home."<sup>13:674</sup>

Therefore, it is necessary to break with the healing paradigms established by the health services and their professionals, healing with the main barrier, which is the absence of an articulated and integrated network of palliative care services in Brazil, which does not allow measuring the impact of this care on existing health policies.

## FINAL CONSIDERATIONS

The research pointed to aspects of the nurse's participation in home palliative care. An important fact to be highlighted

is precisely the lack of public policies that institute palliative care in health care. In this sense, the very concepts attributed to this mode of care are confusing.

The work in home palliative care is done through a socio-cultural construction, since acting in front of the palliative care philosophy required professionals to break with the curing paradigms and establishing care as a priority, this can be evidenced by visits and the creation of bonds in the home environment.

It was possible to highlight the importance of the nurse in this modality of care, which has not yet been structured in the Brazilian health system, trying to care differently for the patient who needs palliative care. The participation of nurses is present in palliative care through the identification of the needs and recognition of the context in which the patient is inserted, performing nursing care, creating relationships between patient, family and nurse, and experiencing significant moments in the accomplishment of care.

The study points out the need for new research that can show the experience of patients, family members, caregivers and professionals involved in home palliative care. It is also suggested the implementation of the subject of Palliative care in undergraduate and postgraduate courses in the health area.

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