

Participation of the family in hospital-based palliative cancer care: perspective of nurses

Participação do familiar nos cuidados paliativos oncológicos no contexto hospitalar: perspectiva de enfermeiros

La participación de la familia en los cuidados paliativos oncológicos: perspectiva de los enfermeros



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ABSTRACT

The objective was to understand the perspective of nurses about the participation of the family in palliative cancer care and to analyze the nursing care strategies to meet their needs. Descriptive and qualitative research, conducted at the National Cancer Institute between January and March 2013, with 17 nurses. Elements of the Roy Adaptation Model were used for the interpretation of the data. Two categories emerged from the thematic analysis: perspective of nurses about the presence and valuation of family in the hospital; and appointing strategies to encourage family participation in care and meet their needs. This participation is essential and represents a training opportunity for the purpose of homecare. Nurses create strategies to encourage it and seek to meet the needs. The results contribute to promote the family adaptation and integrity, in order to balance the dependent and independent behaviors, aiming for quality of life and comfort. Further studies are needed due to the challenges of the specialty.

Descriptors: Oncologic nursing. Palliative care. Hospitalization.

RESUMO

Objetivou-se compreender a perspectiva de enfermeiros acerca da participação do familiar na hospitalização em cuidados paliativos oncológicos e analisar as estratégias de cuidado de enfermagem para atendimento das necessidades daquele. Pesquisa descritiva, qualitativa, realizada no Instituto Nacional de Câncer, entre janeiro e março de 2013, com 17 enfermeiros. Utilizaram-se elementos do Modelo de Adaptação de Roy para interpretação dos resultados. Da análise temática emergiram duas categorias: perspectiva de enfermeiros sobre a presença e valorização do familiar na hospitalização; e apontando estratégias para incentivar a participação do familiar no cuidado e atender a suas necessidades. A participação do familiar é essencial, sendo oportunidade para treinamento visando à assistência domiciliar. Os enfermeiros estabelecem estratégias para incentivá-la e buscar atender às necessidades. Os resultados contribuem para promoção da adaptação e integridade do familiar para equilibrar as condutas dependentes e independentes, visando à qualidade de vida e ao conforto. Novos estudos são necessários pelos desafios da especialidade.

Descritores: Enfermagem oncológica. Cuidados paliativos. Hospitalização.

RESUMEN

Tuvo como objetivo comprender la perspectiva de enfermeros sobre la participación de la familia en la hospitalización en cuidados paliativos oncológicos, y analizar las estrategias de enfermería para satisfacer sus necesidades. Investigación descriptiva, cualitativa, realizada en el Instituto Nacional del Cáncer, de enero a marzo de 2013, con 17 enfermeros, que usó elementos del Modelo de Adaptación de Roy. Por el análisis temático surgieron dos categorías: la perspectiva de las enfermeras acerca de la presencia y valoración del familiar; y las estrategias para fomentar la participación de la familia en el cuidado y satisfacer sus necesidades. Esta participación es esencial, con la oportunidad para el cuidado en casa. Los resultados contribuyen a la promoción de la adaptación y la integridad de la familia, para equilibrar las conductas dependientes e independientes, con el objetivo de su calidad de vida y confort. Se requieren nuevos estudios, por los desafíos de la especialidad.

Descriptores: Enfermería oncológica. Cuidados paliativos. Hospitalización.

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■ INTRODUCTION

Cancer is a very relevant public health problem due to its increasing incidence, prevalence and morbidity and mortality. In developing countries like Brazil, the population still faces difficulty to get access to health services and information, resulting in a large number of cancer patients facing the advanced stage of the disease. In view of this situation, investments are needed in palliative care⁽¹⁾.

Palliative care is promoted by a multidisciplinary team, aiming to improve the quality of life of patients and their family members in view of a life-threatening disease, through the prevention and relief of suffering, early identification and the impeccable assessment and treatment of pain and other physical, social, psychological and spiritual symptoms⁽²⁾.

In the multidisciplinary team, each health professional is responsible for developing holistic care actions. In this study, the nurse's action is highlighted, in view of the dynamic nature of this work, especially in hospital-based care, which rests on the triad that values the health team, the institution and the patient/family, the latter at the center through the establishment of multiple relations and interactions⁽³⁾. Hence, as the professional who together with the other nursing team members is present 24 hours per day during hospitalization, the nurse joints favorable conditions for the identification and direction of actions to attend to people's needs, assuming the family as a care unit, in accordance with the palliative care principles.

In the course of the hospitalization, marked by the exacerbation of symptoms and/or by social demands, in the role of companions, the relatives engage in care and interact with people. The interaction highlighted in this study refers to the family member and the nurse, considering the latter's perspective and nursing care actions in the relative's presence, who needs to be valued as a source in the search for solutions and adaptations for the new reality, in view of the possibility of home care and death⁽⁴⁾.

The justification for this study is based on the emerging nature of the theme, as palliative care is a recent study area and the quality and construction of favorable public policies represent a research priority with a view to its advance⁽⁵⁾. The effort of researchers in the investigation of social phenomena that involve the event of death has grown in the scientific community, but faces challenges linked to different factors, such as the social stigma of cancer and the denial of death. In addition, the inseparability of the family should be taken into account, who gets ill together with its members, and the complexities involved in these relations, considering its structure, composition and function.

Thus, the research questions are: what is the nurse's perspective on the family's participation in hospitalization in palliative cancer care? What care strategies do nurses implement to attend to family members' needs in this context?

The goal was to understand the family members' participation in palliative cancer care, and to understand the nursing care strategies to attend to their needs.

■ METHODS

Descriptive study with a qualitative approach. The descriptive study is characterized by the observation, description and classification of information. When linked to the qualitative approach, it is an in-depth method to describe the dimensions, variations, importance and meaning of the phenomena⁽⁶⁾.

The study was undertaken at the Instituto Nacional de Câncer (INCA), more specifically at the Hospital do Câncer IV (HC-IV), which includes the specialized palliative care unit, located in the city of Rio de Janeiro – Brazil. The HC-IV offers four care modalities, which are: outpatient clinic, home care, emergency care and hospitalization.

The data were collected at the hospitalization unit. The service is located in an eleven-floor building, only four of which house the hospitalization unit, each offering 14 beds, including six nursing wards with two beds each and two individual rooms.

The study participants were the nursing who attended to the following inclusion criteria: being employed by the Institution, and working at the hospitalization unit for at least six months. The sector employs 24 nurses, 17 of whom participated in the study. Three nurses were excluded who were on a maternity leave, one because of only two months of experience at the institution, another one refused to participate and two were not located during the data collection period, i.e. between January and March 2013.

The data collection technique used was the semistructured interview, according to the following script: what is it like for you to have family members present at the sector and often participating in patient care? Do you try to engage the relative in the care that is delivered to the patient? If yes, in what activities and how? At what moments can this participation be positive or negative? Which care strategies do you put in practice to attend to the family members' needs?

The interviews were held individually, at the most convenient time during the shift, at a place free from external noise. The content of the interviews was audio-recorded with the participants' agreement and then fully

transcribed. The interviews were identified by the letter N for nurse, followed by a number indicating the order in which the interviews were held, with a view to guaranteeing secrecy and anonymity.

For the data analysis, thematic analysis was applied, using the theme as the registration unit. This method consists of three phases, which are: pre-analysis, exploration of the material and interpretation of the results⁽⁷⁾. The themes composed the categories that were analyzed according to the conceptual bases identified in a literature review, and based on elements of the Roy Adaptation Model. This model consists of the metaparadigm of nursing: person, environment, health and nursing targets. The importance of this reference framework to analyze the present study data is mainly concentrated in the approach of the person as a system with multiple dimensions and that issues responses that are adaptive or inefficient to the experienced situations. The target of nursing is the delivery of holistic care that considers the confrontation with stimuli, among which the self-concept, role performance and interdependence stand out⁽⁸⁾.

The ethical premises of research involving human beings were respected, in accordance with National Health Council Resolution 466/12. Approval for the project was obtained from the INCA Research Ethics Committee (protocol 97/12).

■ RESULTS AND DISCUSSION

Among the 17 nurses interviewed, it was verified that: the majority is female (82%), the most prevalent age range is between 31 and 40 years of age (53%) and the predominant time since graduation is between 06 and 10 years (71%). A large part of the group indicated working on a fixed job contract (82%), with one to five years of work in hospitalization (88%) and holding a graduate degree in the area (88%).

The analysis of the empirical material revealed two categories that will be presented next.

Nurses' perspective on the presence and valuation of family members during hospitalization

The nurses consider the family member's presence essential, independently of whether they may represent a greater demand for work. This perspective is related to the following prerequisite though: the family member's interest in giving care. Thus, his/her presence contributes to the survey of patient information and represents an opportu-

nity for training in view of the possibility of home care, as observed in the following testimonies.

It always bothers me when there is no caregiver. I prefer having one, no matter if he'll bother and ring the bell, keep on calling you all the time [...]. (N5)

The family member's participation is fundamental, because he's our ally in palliative care. He's not there to assume the nursing care, but to learn how to take care of their ill patient, because we always work with the possibility of discharge.(N8)

[...] during the bedside visit, we ask the family member if he spent the night with the patient, if he knows how the acceptance of food is going, the evacuation and whether there is any complaint. Because, when the family member is there, he perceives when the patient's condition changes[...]. (N2)

The nurse's perspective on the family member's presence is positive, considering the establishment of communication in the exchange of information about the hospitalized person's clinical condition for example. In addition, the encouragement of the family member's presence during hospitalization aims to, among other aspects, grant the hospitalized patients safety and comfort, favoring the shortening of this period and the return home. The nurse recognizes this phase as an opportunity for the family member to learn or enhance the accomplishment of basic care and minimize their own difficulties related to the disease and the treatment⁽⁹⁻¹⁰⁾. From the perspective of the Roy Adaptation Model, through interactions and the valuation of the environment, the nurse can contribute for the family member to find a balance and ways to adapt to the reality according to his/her own coping mechanism⁽⁸⁾.

Among the positive aspects the nurses indicate as contributions to the valuation of the relative's presence in the context, the following stood out: commitment, participation in care, orientation with regard to palliative care, good relationship with the hospitalized patient, as well as with the nursing team.

I think that the participation is very positive, during the bed bath for example, because instead of two nursing technicians going to the bath, I can arrange only one, which makes things a lot easier in relation to the team. The relative helps a lot in that sense. It is also positive when he understands what palliative care is and that the hospital's proposal is to improve the patient's clinical condition and

return the patient home [...]. He ends up becoming practically a team member [...]. (N11)

Participating relatives are allies of the nursing team, in view of their contribution to the operation of the nursing process for example, providing information or support in care actions, which changes the dynamics of teamwork in the distribution of staff members on the daily work scale.

The safe relation granted to the hospitalized patients as well as to the nursing team can be considered a way to promote the quality of life as, for this purpose, the family should always be present⁽³⁾. This presence is not free from negative interferences though. In some cases, the family members can refuse to participate in the care; deny the incurable disease; have a knowledge deficit about palliative care or cognitive limitation; have no aptitude for care; having no emotional balance; have no time available; being elderly or suffering from other illnesses; besides the influences in cases of earlier conflicts. These conflicts were exemplified in the following testimonies.

[...] there are companions whom we see have no equilibrium to be here, or who do not understand what palliative care is. So, sometimes, I think they are not helping as we expected, and that ends up causing further anxiety to the patient. (N2)

The negative side is when they selected a person in the family who is in no conditions to give care. Because there are people who want to help but are unable to and we are not always able to train them [...]. (N16)

[...] sometimes it's one elderly taking care of another [...]. Although they are the most willing to give care, there are limitations to perform the care. You need to take great care when giving directions about the medication and try and make things as easy as possible so that they don't face difficulties at home. (N11)

The negative aspects represent challenges for the nurse and other team members, who need to act effectively and actively, clarifying doubts and encouraging positive attitudes⁽³⁾. A broader understanding of the situation is needed, with a view to avoiding unfounded prejudices, as most cases relate to complex life histories, with developments in all spheres, i.e. emotional, spiritual and cultural. Thus, various aspects need to be addressed with a view to acceptance and coping, however, without forgetting the limits and the individual needs. In addition, the professionals themselves need to be prepared to manage conflicts,

which are common in stressful environments of vulnerability to death⁽¹¹⁾.

When the family members lack orientations and are inserted in the palliative care context, their presence becomes negative, as their lack of knowledge and emotional disequilibrium can cause anxiety, conflicts and a feeling of helplessness. This situation can contribute to extended hospitalizations, sometimes due to social demands.

Considering the family member's participation in the context, based on the positive and negative aspects from the nurses' perspective, the person's behavior with regard to the adaptive modes generates support to allow these professionals to identify adaptive or inefficient responses. In the framework of integrality and interdisciplinarity, in view of the family member's coping difficulties, the nurses need to attempt to act on the adaptive modes: the self-concept (values, beliefs and emotions); role function (person's social interaction patterns); and interdependence (human value, affection, love and assertion patterns)⁽⁶⁾. Therefore, effective communication is highlighted as the main strategy, based on the offering of comforting words and other expressions of kindness, such as a hug, exchange of looks, cuddle or a shoulder to cry on⁽⁴⁾.

Appointing strategies to encourage the family members' participation in care and attend to their needs

In search of the relatives' adaptive responses to cope with the situation, marked by anticipated mourning and the experience of death in life, the strategies the nurses adopt are related to the demands, mainly considering the conditions, circumstances and influences that surround and affect their behavior. Thus, among other strategies, training for care is highlighted, through demonstration, dialogue, constitution of groups of family members, interdisciplinary approach and use of explanatory leaflets, as highlighted in the following testimonies.

[...]in case of pressure ulcer, for example, I show that it happened, but can be reverted. So we are always picking up the explanatory leaflets. We have the social service's lectures with the families. In that case, we've got a nurse, nutritionist, social worker, physician and the psychologist. So, to avoid turning into something tiresome, we join a group of family members to talk and clear doubts. Because sometimes people have the same doubts, and there are people who are ashamed to ask and end up using the opportunity and ask too. So the family members end up feeling more at ease. (N7)

[...] in case of subcutaneous medication for example, it's important for them to train, as they'll need to do it at home. They need to hold the material, puncture here and go home feeling much safer. (N5)

In these cases, communication turns into an element that can minimize the family members' difficulties. A relationship of trust needs to be established so that the family members feel at ease to express their difficulties, valuing their preliminary knowledge. The encouragement for the relatives to participate in the groups is an important strategy. It is highlighted, however, that during the hospitalization, they should not be trained to assume nursing functions in response to a possible lack of human resources.

The nurse's strategies to train the family members should be established based on true information and communication, so as to engage the people involved and value the moment that is being experienced⁽¹²⁾. Based on the Roy Adaptation Model, it is considered that this person is capable of acting for a common goal and, as adaptive beings, are able to adapt and create changes in the environment, which will be strongly evidenced if the opportunity for home care arises, free from the hospital bureaucracies and routines. On the other hand, the nurses should pay attention in order to identify the demands of each situation and to the internal resources each person has available, in which each experience is individual⁽¹³⁾.

Communication can be considered as the main resource to promote the adaptation and improve the coping with the situation the family member experiences. It can happen in different ways, including the use of leaflets and individual and group activities, involving the multidisciplinary team. It is highlighted that the family needs to bond and feel safe, which is made easier when the nurse's posture is marked by availability. Human resource difficulties, however, especially during the nighttime shift, can compromise the quality of care⁽¹⁴⁾.

Regarding the aspect of human resources, attention is needed to the possibility of confounding roles. The nurse's intervention in the supervision of nursing team actions and in the training of family members is fundamental, clearly aiming to prepare for discharge. Composing teams and structures to offer palliative care to the population is not an easy task. Therefore, the strategy to develop the family members' skills for home care should be encouraged, as one of the main difficulties is the feeling of helplessness in the experience of cancer⁽¹⁵⁾.

In view of the rapid progression of cancer in most situations, considering the physical aspects of the adaptive model, the nurse can prepare the family for the changes,

focusing on the strengthening of the regulatory or coping mechanism, aiming for the patient's quality of life and comfort⁽⁸⁾.

Among the strategies to benefit the family members, the nurse's mode of organizing, planning and implementing actions to attend to their needs was also highlighted. This nursing process is valued when considered based on theoretical models, contributing to the unification of activity modes, to the application of well defined and evidence-based criteria.

The actions depend on the family members' demands, in which their earlier experiences should be considered, and that their behavior is reflected by the interpretation they can reach of the moment they experience. In view of the complexity of the context, the demands are related to actions that include listening, giving proper attention, reaching out and welcoming. Nevertheless, the work burden can impair the development of this care sphere, which on the opposite encourages interdisciplinary work. As an element of the environment, however, the nurses take on decisive responsibilities in the family members' adaptation process, based on empathy, attitudes, knowledge and the ability to interact, as observed in the following testimony.

[...] imagine you telling a person that her father is dying? I think the main know in all that is communication, because it is fundamental to minimize this relative's difficulties. The way you address that person, you knowing if she is understanding what you are saying [...]. The availability has to come from both sides, the issuer and the receiver, I need to be available to give you some time and you need to be available to listen to me. I always try to put myself in that person's place [...]. (N5)

The factors that can interfere in the ability and use of these strategies include the prejudices and fears in view of cancer, which is considered a taboo. This fact can negatively affect the appropriate approach of the family member, through a potential threat to life. The difficulties to talk about the diagnosis/prognosis can make the professionals assume paternalistic or distancing attitudes⁽⁹⁾.

The way the communication is established can contribute to approximation or distancing among the stakeholders, which directly affects the quality of care, in view of the impossibility to truly diagnose the problems besetting or affecting the family members. Communication should be a tool for effective intentional interaction, with adaptations according to each situation⁽⁵⁾. Thus, based on communication and sensitive listening, problems can be identified that are not always expressed.

The individual needs need to be perceived and respected in a singular manner, approaching the disease situation the relative experiences to the possibilities of life inherent in each person, considering the family in an integrated manner, participating in the decision processes, receiving appropriate orientations and understanding family particularities⁽¹⁶⁾. Thus, the nurse will be contributing to promote the stakeholders' adaptation and integrity, enabling the family to take initiative and achieve the objectives of care, as well as a support base in the form of an available system, in a balance between dependent and independent conducts.

■ FINAL CONSIDERATIONS

The nurse's perspective on the family member's presence during hospitalization in palliative cancer care tends to value the positive aspects, considering the opportunity to train them for home care and welcome them in the attempt to attend to their needs, which are mostly related to information, in which the establishment of effective communication is fundamental.

The negative aspects appear as challenges for the nurse and the health team, in view of the complexity of human relations and problems.

The nurses aim to identify the family members' needs according to the dynamics of the shift and, to attend to them, need to be available and conduct their practice from an interdisciplinary perspective. Thus, they face problems with the lack of human resources, which can compromise the quality of care or provoke role confusions in the thin line between the relative as a companion and as a protagonist in care.

The family should be a care unit, in which the nurse and the health team are responsible for establishing partnerships based on a relationship of trust. The patient and his/her family make up an inseparable pair, immersed in a global context, often experiencing emotional, social, economic and cultural difficulties that impose limits to cope with the situation. The experiences are unique and need to be valued.

Among the study limitations, it is highlighted that it only involved family members of cancer patients and was

restricted to the hospitalization context, as this care mode involves other important modalities, like home care. Therefore, the expansion to other contexts and realities in palliative care is suggested, in the attempt to establish the most important aspects to attend to the family members' needs, also aiming for their quality of life and comfort.

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