ANALYSIS OF NURSING CARE AND THE PARTICIPATION OF FAMILIES IN PALLIATIVE CARE IN CANCER¹

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ABSTRACT: This qualitative study aimed to analyze, through the vision of family, the nursing care provided to patient affected by advanced cancer during the hospitalization, as well as their participation in care. The Grounded Theory was used as a methodological reference framework. Data were collected by the technique of semi-structured interview, at hospital palliative care - Brazil. Eight family members participated in the study. Three categories were identified: Analyzing the nursing care provided to patient with advanced cancer on a day-to-day of the hospitalization; Emphasizing the importance of your presence in the context, and Manifesting the family who cares and need to be cared. The family believes that nursing care should be based on the empathy, good humor, competence, and communication; participates in the care; and may have needs for physical and psychosocial. Nursing must contribute to closer relations with family members, and seek to serve their needs, aiming at quality care.

DESCRIPTORS: Oncologic nursing. Hospice care. Professional-family relations.

ANÁLISE DO CUIDADO DE ENFERMAGEM E DA PARTICIPAÇÃO DOS FAMILIARES NA ATENÇÃO PALIATIVA ONCOLÓGICA

RESUMO: O estudo objetivou analisar, por meio da visão dos familiares, o cuidado de enfermagem prestado ao cliente acometido por câncer avançado, no período da internação hospitalar, bem como a sua participação neste cuidado. Estudo exploratório, qualitativo, que utilizou a Teoria Fundamentada nos Dados. Os dados foram coletados por entrevista semiestruturada, no Hospital do Câncer IV - Brasil. Participaram oito familiares. Da análise emergiram três categorias: Analisando o cuidado de enfermagem prestado ao cliente com câncer avançado no dia a dia da internação hospitalar; Ressaltando a importância da sua presença no contexto; e Manifestando o ser familiar que cuida e precisa ser cuidado. Os familiares valorizam que o cuidado de enfermagem seja empático, com bom humor, competente, pautado na comunicação; participam do cuidado e podem apresentar necessidades de ordem física e psicossocial. A enfermagem deve contribuir para o estreitamento das relações com os familiares, e buscar atender suas necessidades, visando a qualidade do cuidado.

DESCRITORES: Enfermagem oncológica. Cuidados paliativos. Relações profissional-família.

ANÁLISIS DE LOS CUIDADOS DE ENFERMERÍA Y LA PARTICIPACIÓN DE LAS FAMILIAS EN EL CUIDADO PALIATIVO ONCOLÓGICO

RESUMEN: El estudio tuvo como objetivo analizar los cuidados de enfermería prestados a los pacientes que sufren de cáncer avanzado en el período de hospitalización, así como su participación en el cuidado. Estudio exploratorio, cualitativo, que utilizó la teoría fundamentada en los datos. Los datos fueron recolectados utilizando la entrevista semiestructurada, en el Hospital del Cáncer IV - Brasil. Los participantes fueron ocho miembros de diferentes familias. Tres categorías se identificaron: El análisis de los cuidados de enfermería prestados a los pacientes con cáncer avanzado en el día a día de hospitalización; Destacando la importancia de su presencia en el contexto, y Manifestando una familia que cuida y necesita de cuidado. Los familiares creen que el cuidado de enfermería debe ser empático, con buen humor, competente, sobre la base de la comunicación; participan en el cuidado, y pueden tener necesidades físicas y psicosociales. Enfermería debe contribuir al fortalecimiento de las relaciones con miembros de la familia, y tratar de responder a sus necesidades, con miras a la cualidad de la atención.

DESCRIPTORES: Enfermería oncológica. Cuidados paliativos. Relaciones profesional-familia.

INTRODUCTION

Cancer represents a public health problem in Brazil and around the world and an extremely relevant epidemiological condition, considering incidence, morbidity and mortality levels. According to data by *Instituto Nacional do Câncer* (INCA), concerning estimates for 2012, also valid for 2013, in total, 257,870 new cancer cases are expected for men and 260,640 for women, including non-melanoma skin cancer cases.¹

The World Health Organization (WHO) estimated that, by 2030, 27 million cancer cases can be expected, 17 million cancer deaths and 75 million people living with cancer per year. This reality, particularly in developing countries like Brazil, demands public health policy investments to respond to the population's needs, particularly in palliative care, in combination with the concerning demographic transition and aging of the Brazilian population in recent decades.¹

Palliative care comprises a form of care delivery that fits into a philosophy that furthers care to people, to the detriment of actions essentially aimed at curing diseases. In view of a lifethreatening progressive and irreversible disease, care measures aim for comfort, the maintenance of quality of life and human dignity in the face of the dying process. This care mode is guided by the principles of bioethics and seeks to: preserve people's autonomy on their life and their own death; truthfulness in the relations established among professionals, clients and family members; avoid futile therapies that can increase or extend suffering, with a view to beneficence and therapeutic proportionality; besides comprehensive care to clients and family members' needs, which go far beyond the physical aspects.²⁻³

In cases of human terminality resulting from a chronic health condition like cancer, besides physical symptom control, attention is needed to the care needs that comprise psychosocial, emotional and spiritual aspects, which flourish in that phase of the disease. With a view to comprehensive and high-quality care, the health team should work in an interdisciplinary perspective, joining practices and scientific knowledge, in view of the complex problems that affect human beings, complex beings, and influence their social context.⁴

The peculiarity of clients' profile in palliative oncology care derives from the great care demand

and clinical instability, besides the presence of relatives with their own needs, requiring care actions that include education and support in the mourning phase for example.⁵

During hospitalization, specifically in palliative oncology care, the complexity of the context is well evidenced in the dialogues between order and disorder, death and life, in uncertainties and unforeseen aspects, as the indication of this care results from highly refractory and discomforting symptoms and/or severe social problems, which may mean the proximity of death.⁶

In this scenario, it is the nursing team that constantly stays with clients and their relatives, 24 hours per day, spending more time on end-of-life client care than any other professional.² As, in most cases, clients are accompanied by relatives – considering that families can comprise individuals joined by natural bonds, affinity or expressed will⁷ – the following hypothesis guided the study: relatives are present in the hospitalization context, perceive how nursing care happens, participate and present their own needs, and need to be considered in nursing care management.

In this sense, the following questions are asked: how do family members consider the nursing care delivered to clients with advanced cancer during hospitalization? And how do they participate in this care?

The aim of the study was to analyze, through family members' perspective, the nursing care delivered to clients with advanced cancer, during hospitalization, at a specialized palliative oncology care unit, as well as their participation in this care. What justifies the study is the need to provoke reflections in the relatives of advanced cancer clients at hospitalization units about their role with regard to the nursing team, and also contributes to nurses' elaboration of strategies to improve nursing care management, in view of family members' difficulties and/or needs involving these clients.

METHOD

This exploratory study with a qualitative approach was part of the doctoral dissertation entitled "Nursing care management in palliative oncology care". Exploratory studies serve to get to know a given reality or study phenomenon as it presents itself, through the study design, bib-

liographic survey, interviews with people who went through or go through practical experiences with the research problem, and document reading and analysis. The choice of the type of approach derives from the production of non-achievable results through statistical procedures or other means of quantification.⁸⁻⁹

The study was made feasible through the use of the methodological framework of Grounded Theory. The intent when using this method is to support concepts on data extracted from empirical realities, involving subjects in constant interaction processes. The way they explain their statements and actions is studied.¹⁰

In Grounded Theory, data collection and analysis processes happen simultaneously, which characterizes compared analysis, and the actual conception of the research problem starts to emerged from the data themselves.9 Coding processes structure data analysis, the first refers to open coding, which seeks preliminary codes based on line-by-line analysis of gross data, which will serve as the blocks to build the categories, subcategories and respective components; the second refers to axial coding, when the categories and subcategories are defined, in search of abstraction to the central category; and, finally, selective coding takes place, when the elements of the paradigmatic model are used to interconnect the categories and reveal the central phenomenon in the study.9

The use of elements of the paradigmatic model to reveal the central study phenomenon and construct the theoretical matrix serves to better integrate structure and process. Thus, the coded data are joined, ordered and interconnected, taking into account the structural conditions and the process, related with actions and interactions in time, space, with people, organizations and societies, in response to certain problems and topics. Causal conditions, the context and intervening conditions are part of the structural conditions, which together answer the questions: why, where, how and when. The process concentrates the action-interaction strategies and consequences. Strategies can be individual or collective and mean actions towards problems, and consequences represent the results achieved or expectations.9

Study participants were eight relatives, who complied with the following inclusion criterion: serving as a companion, in the hospitalization

context, during data collection. All participants signed the Informed Consent Term, in compliance with the ethical aspects of National Health Council Resolution 196/96. Also, in accordance with requirements for research involving human being, as established in the same Resolution, approval for the study was obtained from the Research Ethics Committee at the INCA, under opinion n. 45/10.

Data were collected at the hospitalization unit of *Hospital do Câncer* IV (HC-IV), which is the unit specialized in palliative oncology care at the INCA, located in the city of Rio de Janeiro, Brazil.

Data were collected between October and December 2010. The data collection technique was the semistructured interview. This is the recommended technique to use Grounded Theory, as it permits greater flexibility to clarify essential points in knowledge about reality. The following script guided the interviews: How do you believe nursing should attend to your relative's care needs? How do you believe nursing should attend to your own care needs? Talk about what happens here. Survey negative and positive points. How do you assess your participation in care for your relative? What do you think could improve? How could this be done for you?

Each interview was held individually, digitally recorded and then fully transcribed. This already characterized the start of the analysis, in the open and axial coding processes, in search of codes. This phase was performed for each interview, in a cyclical and dynamic process between data collection and analysis, through constant comparison and interaction between the gross interview data and the created codes. The strict and systematic method of Grounded Theory was followed, so as to construct the conceptual categories, with their respective subcategories and components.

Data analysis revealed three conceptual categories, centered on the family members' view on nursing care delivered to hospitalized clients with advanced cancer and on their participation in this care, which were: Analyzing the nursing care delivered to advanced cancer clients in daily hospitalization; Highlighting the importance of their presence in the context; and Manifesting the family being who takes care and needs care.

Discussion of the data was based on the contributions of the Science of Complexity and

the precepts of palliative care, as well as on other authors who discuss the theme in the authors' nursing knowledge and critical area.

RESULTS

Eight relatives participated in the study, five women and three men. The most prevalent age range was between 31 and 40 years, with three relatives, followed by the groups between 41 and 50 and between 51 and 60 years old, with two relatives each. One family member was between 20 and 30 years of age. Concerning education, four participations indicated they had finished secondary education, one had finished primary education, two held a higher education degree, while one had not finished higher education. As for religion, all participants informed they were religious, that is: evangelical (50%), catholic (37.5%) and spiritist (12.5%). Four family members were the respective clients' children, two were siblings, one was a friend and the other a son-in-law. The relative's mean time of stay with the client was 11.25 days, ranging from two to 30 days. With regard to knowledge on the patient's illness and clinical condition, only two relatives informed partial knowledge. In both cases, patients were hospitalized at the unit for the first time, with rapid evolution of the disease and worsening of the clinical condition, according to the participants.

Category 1 - Analyzing the nursing care delivered to advanced cancer clients in daily hospitalization

This category was identified as a consequence in the use of the paradigmatic model and comprised, according to the relatives, the achieved results or expectations related to nursing care delivered to hospitalized advanced cancer patients.

The category presents aspects of how the family members envisage the nursing professionals' care practice, whether positive or negatively. It consists of two subcategories: 1) Identifying positive aspects of nursing care in response to clients' needs; 2) Appointing care problems.

The first subcategory, which highlights the positive points of nursing care in the attempt to respond to clients' needs, contains the following components: praising nursing care; and saying

what you consider essential for good attendance, as observed in the following testimonies: [...] I think that the nursing team attends well. There's nothing I can say, because they're always here, always smiling, talking, in a good mood [...] (interview H); [...] I find it essential for the nursing team to respond to the needs rapid and efficiently, depending on the degree of the patient's need [...] (interview I); [...] at the moment she's being very well attended, people around her are working and treating her with kindness. The nursing team is concerned with the pain and also with her hygiene, I think that's the main thing, considering that her current condition is very severe [...] (interview L).

The following components are part of the second subcategory, which covers the negative aspects the family members highlighted about the nursing team's care practice: criticizing nursing care; saying what needs to change for good attendance; and suggesting strategies to change.

In criticism, issues stood out related to the lack of communication among professional, client and relative, as well as among nursing and health team members themselves; to some team members' bad mood, to the non-empathetic relation and to absence at some moments. As rehospitalization is common at the unit in view of the clients' clinical instability, the meaning constructed in a given experience entails repercussions for current experiences, especially reminding negative ones, as observed in the following testimony: [...] at that moment, the team is present, but there was another occasion, when she stayed on another floor, when I didn't feel much presence [...] (interview L); Another testimony: [...] when the person is relaxed, arrives and makes jokes, transmits positive energy, that cheers up the patient, makes him laugh. Now, when a person gets here really tight and does not pay proper attention, I think it makes things difficult. Even when giving us information, she doesn't even say what medicine she's giving. We end up not even asking, afraid [...] (interview N).

In the component about what needs to change with a view to good attendance, the discourse of four family members converged, as follows: [...] *I don't think it has to change, because she's being well attended, very well taken care of, and now it's in God's hands* [...] (interview M). On the other hand, the remaining relatives highlighted the following, for example: [...] *although the problem did not occur this time, I think there should be greater exchange*

in the team. Because, in some teams, you perceive that they don't coincide much. They may be having a bad day [...] (interview L).

In the strategies for change, the family members demonstrated concern with the professionals' own needs, whether related to physical and emotional exhaustion or to the need for training to know how to deal with difficult and common situations in palliative care. Suggestions include: [...] they could have some activity, like 15 minutes more at lunchtime to relax. There could also be a massage room to relax when the person is very tense. I find that very important, to try and see the employee's side [...] (interview I); [...] I think that sometimes, there should be, I won't even call it a course, but a lecture, showing to the team, raising awareness that everyone here is alike, independently of being a physician, being a nurse, being a psychologist, they're all human beings. And to transmit to them that, in this profession, you need love, kindness, respect. And, here, many patients are hospitalized to leave, to go away so, may the end be comfortable, in peace [...] (interview P).

Category 2 - Highlighting the importance of their presence in the context

This category was identified as an action-interaction strategy in the use of the paradigmatic model, which includes family members' actions towards the client's problem or care need. It consists of one subcategory: Participating in care, which addresses the value of the family member's presence at the client's side, during hospitalization, whether to offer emotional and psychological support or to participate in care itself, developing actions the nursing team can delegate or advise on, like for example: help with hygiene, feeding, walking or position changing.

Components of the subcategory are: offering clients psychological and emotional comfort; and helping the client, other hospitalized persons and the nursing team.

Among the testimonies that characterize this category, the following stand out: [...] I think that the family is very important, to be here always, with her, showing that she is not alone [...] (interview H); [...] I think I grant my father some comfort, because nobody likes to be in hospital, no matter where. I think the relative brings a small part of home here, for him, so that he can feel more comfortable, more protected [...] (interview P); [...] when the team asks to help, I help. Yesterday they asked me to help

and turn my sister and I helped. I put the feeding, because she's got a tube and the nursing team taught me very well to place it, remove it and wash it with water [...] (interview M); [...] I really love what I'm doing, because I think God is showing me this gift. I help my sister, and it's not difficult for me. And the other people I help with feeding, or bathing if necessary [...] (interview J).

Category 3 - Manifesting the family being who takes care and needs care

This category was identified as the context in the use of the paradigmatic model, presenting a set of conditions that combine to produce a specific situation, in this care related to the complexity of the hospitalized clients' profile. The context characteristics are evidenced by the family member's needs, who can get ill together with his/her loved one, is exposed to physical and psychological fatigue and needs to conquer challenges and acknowledge his/her limits.

This category comprises two subcategories: 1) Unveiling one's needs; and 2) Hiding one's needs, as the family members sometimes recognize and sometimes mask their needs, with a view to showing that they are always strong and able to bear the situation they experience.

The first subcategory addresses the needs the family members unveil related to the stress of the hospitalization routine, fatigue and sadness, as well as the nursing team's participation to support them in this experience. Components are: going through the caregiving experience; and receiving attention from the nursing team.

The following testimony characterizes this experience well: [...] although sometimes I get weak, weepy, because we end up getting involved in other people's problem here. Because, after we get here and spend time with the patient, we can see it's one family here, everyone's going through the same problem. So we absorb that [...]. Sometimes you think you've reached your limit, then you need to go home, breathe a little [...]. And then I come back, I come back well, I come back renewed [...] (interview J).

Concerning the nursing team's participation: [...] sometimes I get stressed, and nursing contributes quite a lot. Because people are very calm here. They don't make things harder, they always try to work to make things easier, for you to feel better [...] (interview L). Another testimony underlines nursing's participation in reducing family mem-

bers' deficient knowledge about the disease and the clients' current condition, as a way of seeing to their needs: [...] when I got here the physician wasn't in, and the nurse updated me on her case, the surgery she has to get, and everything was clarified [...] (interview H).

The second subcategory evidences how difficult it is for relatives to recognize their own needs in the situation they experience, with the following component: experiencing difficulties to recognize one's own needs as a caregiver. The following testimony characterizes the subcategory: [...] I don't have any needs right now. There even was a psychologist talking to me, and I said I'm a very calm person. And I'm the only child who's like that with her. I've been with her since 2001, accompanying this treatment, so I'm calm. There's nothing stuck here I can externalize, things I may want to talk about with people. I'm always calm [...] (interview O).

DISCUSSION

The context of family members' experience in palliative oncology care is complex, especially in view of the possibility of death, disabilities and physical and psychological burden due to daily contact with suffering and pain of their loved one. Considering the high level of uncertainty, mainly related to death, one needs to monitor the flow of events and observe what emerges from them, which remits to the need to observe reality and attempt to adapt to it. Due to rapid changes and unpredictable situations, however, family members may experience difficulties to go through that reality, manifesting care needs.

The family members saw the nursing team's participation in attendance to the relative's care needs in actions that include the way of being, doing and living with other people, highlighting empathy, good mood, calmness, competence, skill, agility and communication. According to the relatives, actions that contribute to good client care can be guided by experience-based practices, as well as deduction and induction processes, as reality in general comprises order, disorder, interaction and organization. Hence, considering that the notion of order consists of different levels, it contributes to the possibility that the nursing team will foresee situation, enhancing professionals' anticipation, especially concerning communication when the client's clinical situation worsens. This is aimed at establishing trust, security in the relations established and preparing for mourning. 12-13

Thus, the nursing team aims for organization, mainly by attending to clients' needs, disclosing the importance of problem-solving actions, according to the problem situation and disease evolution, working towards care objectives that are in line with the precepts of palliative oncology care.

In the context, family members' presence is valued because of the opportunity to participate in care and contribute to their loved ones' physical and psychological comfort, who may be leaving, in the dying process. For relatives to say at the nursing units as companions, often fulltime, it is fundamental to establish a constructive interpersonal relation between the former and the nursing and health team members. In that sense, effective communication is the main way of attending to the family members' needs, whether in the relation between nursing team, client and relatives or between the nursing and health team, within an interdisciplinary perspective.¹³

It was evidenced, however, that communication errors occur sometimes between the nursing team, clients and family members, which deprives care delivery of its characteristics in the context. The way communication is established can contribute to further approximation or distancing among the stakeholders, which directly influences care quality, in view of the impossibility to truly diagnose the problems that afflict or affect the family members, as well as the way they start to analyze care.

It is certain that each person, professional, client or family member sees what is being experienced and how that is occurring differently, which includes the way nursing care is delivered. It should be highlighted, though, that although family members have demonstrated that nursing team professionals can also present their own needs, they go through a particular experience, rooted in suffering, pain and often denial. This demands the care professionals' sensitivity, empathy and therapeutic relationship, free from authoritarian behavior, which may be imbued in their position, in view of caregivers and care receivers.

Communication errors may be related to two main aspects, the fact that this is a hospital environment, where power relations are evident, including the power of knowledge. When manifested more strongly, these create favorable conditions for conflict; and the possibility that family members will behave with aggression and resistance, going through the phase of denial, difficulty to cope with the problem and inconformism.¹⁴⁻¹⁵

With a view to contributing to attendance to family members' needs and the dynamics of family members' participation in care, the nursing team should work based on dynamic and flexible reference frameworks, in a participatory sphere, tightening relations, with respect for people's autonomy.16 In an environment in which one constantly lives with suffering and pain, solidarity is inherent in human beings. And, in this context, flexibility is paramount in care actions and their relations, which includes skills gains in learning to live with other people. According to each case prognosis, the family members' participation in care is a nursing care strategy to train them, in view of the possible preparation for the client's discharge.

In all categories that were evidenced, communication is expressed in some way and is very valuable. It is fundamental for the nursing team to develop and consciously use this skill, which demands preparation, in the professional education as well as training contexts, whether to attend to clients and family members' needs or to cope with difficult situations, considering that daily professional practice entails stress, physical and psychological fatigue, exposing individual and collective limits.¹⁷⁻¹⁸

The relation between nursing team members' care for the "I - human being" and the "I - professional being" should contribute to humanized care, as these care dimensions are interwoven, representing the "uni-duality" of human beings. They cannot be separated. In situations when the person who is receiving care is suffering and in pain, however, the "I - professional" prevails as a strategy to cope with reality, but which can devaluate and dehumanize care, exposing contradictions related to care/lack of care. Care for the "I - human being" is often left aside, and only manifested in view of some, especially physical problem, like pain, leading to self-medication. This problem is mostly related to the professionals' devaluation of their own complaint and the lack of the professional's time. It is important, however, for professionals to be concerned with care for themselves, so as to integrate the physical, spiritual and mental dimensions.19

This concern related with care for the "I human being" should also be the focus of nursing professionals' attention to the relatives, as they often stay at the hospital full-time, without taking care of themselves in both physical, in view of possible already established chronic health conditions, and psychological terms, in situations when they experience anticipated mourning. Therefore, in the team work environment, nurses need to put in practice management strategies to reach the care objectives, understanding the feelings involved in the relations, respecting each person's limits, practicing comprehensive care, based on interdisciplinary articulations, promoting support groups for family members to exchange experiences and improve their disposition to cope with the situation, as well as to provide family members with nursing care orientations, with a view to maintaining a healthy work environment.20

Based on the shared view of the beings who take care and need care, both nursing professional and family members, efforts should be directed at the desire to do good, in a relation and action nourished by the desire to help the other, and see to his/her needs.²¹ Nevertheless, the challenge of dealing with death and dying every day may arouse feelings of impotence, fear, anxiety and denial, involving individual and group experiences, as well as (un)awareness of one's own vulnerability and the (un)certainty of death that accompanies us.²²

FINAL CONSIDERATIONS

In care delivery to hospitalized clients with advanced cancer, family members value that nursing care delivery comes with a good mood, efficiency, agility, dedication, kindness, attention and empathy, especially considering the possibility that this is a moment of farewell from their loved ones. They consider that the main problem nowadays derives from some team members' inability to communicate effectively, and indicate that attention needs to be paid to professionals' own needs, who are human beings and need care.

When participating in care, the relatives highlight the possibility of contributing to their loved one's emotional and psychological comfort during hospitalization, and also of delivering actual care actions, which they see as a form of helping their relative, other hospitalized

patients and the nursing team in daily dynamics at the wards. Also, it represents one of the management strategies nurses adopt, comprising family members' training and education, in view of the possibility of the client's discharge from hospital.

Based on the precepts that characterize care delivery in palliative oncology care, in view of the complexity of the context and constant human interactions, the study addresses the need for cooperative, sensitive and flexible nursing work, free from power relations, so as to stimulate the family's active participation in client care and heed their own needs and limits.

Thus, nursing professionals need to develop communication skills, in view of difficult and common situations in palliative oncology care, in favor of participatory management. The actual demand, which involves professional training, adequate work conditions and humanization, as these are persons taking care of persons, reflects the need for further research, especially emerging from the practical context, based on the meaning attributed to empirical data. This serves to create conditions for nursing care to happen in a highquality environment, considering families and clients as inseparable, complementary and, why not, sometimes antagonistic subjects, increasing the challenge and revealing the complexity of human interactions.

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