

NURSING TEAM ACTIONS FROM THE PERSPECTIVE OF FAMILIES OF PATIENTS UNDER PALLIATIVE CARE

ATUAÇÃO DA EQUIPE DE ENFERMAGEM SOB A ÓTICA DE FAMILIARES DE PACIENTES EM CUIDADOS PALIATIVOS

ACTUACIÓN DEL PERSONAL DE ENFERMERÍA DESDE LA PERSPECTIVA DE LOS FAMILIARES DE PACIENTES EN CUIDADOS PALIATIVOS

Rudval Souza da Silva¹
Rodrigo Duarte dos Santos²
Cássia Luiza de Souza Evangelista³
Christielle Lidianne Alencar Marinho⁴
Gerlene Grudka Lira⁵
Magna Santos Andrade⁶

¹ RN. PhD in Nursing. Adjunct Professor. University of Bahia – UNEB, Campus VII. Senhor do Bonfim, BA – Brazil.

² RN. Municipal Secretariat of Health. Juazeiro, BA – Brazil.

³ RN. UNEB, Campus VII. Senhor do Bonfim, BA – Brazil.

⁴ RN. MS in Hebiatrics. Assistant Professor. UNEB, Campus VII. Senhor do Bonfim, BA – Brazil.

⁵ RN. MS in Health Sciences. Assistant Professor. University of Pernambuco. Petrolina, PE – Brazil.

⁶ RN. MS in Public Health. Assistant Professor. UNEB, Campus VII. Senhor do Bonfim, BA – Brazil.

Corresponding author: Rudval Souza da Silva. E-mail: rudvalsouza@yahoo.com.br

Submitted on: 2016/05/25

Approved on: 2016/12/19

ABSTRACT

This study aimed to know the perception of family members about the actions of the nursing team in caring for patients under palliative care. This is an exploratory-descriptive and qualitative study conducted in an oncology outpatient clinic. Seventeen family caregivers of patients under palliative care participated in the study. Data were collected in February and March 2015 through interviews, subjected to Bardin's content analysis and discussed according to the philosophical principles of palliative care. Three thematic categories were identified: feelings expressed by relatives when the loved one's diagnosis of cancer affects the family's quality of life; promoting care practices that relieve pain and suffering; and chemotherapy: a moment of pain and suffering. Results led to the conclusion that accompanying a loved one under palliative care represents suffering also for family members, given the difficulties experienced by them, in addition to the conflicts and feelings that are triggered by coping with the disease and the fear of death. In this scenario, the nursing staff can act as a protagonist in the link between the palliative care team and the patient-family unit, favoring the promotion of bio-psycho-social-spiritual welfare.

Keywords: Palliative Care; Family; Caregivers; Oncology Nursing.

RESUMO

Este estudo teve por objetivo conhecer a percepção de familiares acerca da atuação da equipe de enfermagem no atendimento a pacientes em cuidados paliativos. Trata-se de estudo exploratório-descritivo de abordagem qualitativa, realizado em um ambulatório de Oncologia. Participaram 17 familiares cuidadores de pacientes em cuidados paliativos. Os dados foram coletados nos meses de fevereiro a março de 2015 por entrevistas e submetidos à análise de conteúdo em conformidade com o método de Análise de Conteúdo de Bardin e discutidos segundo os princípios filosóficos dos cuidados paliativos. Emergiram três categorias temáticas: sentimentos expressos pelos familiares quando o diagnóstico de câncer em um ente querido afeta a qualidade de vida da família; promoção de práticas de cuidar que aliviam a dor e o sofrimento; e quimioterapia: momento de dor e sofrimento. Concluiu-se que acompanhar um ente querido em cuidados paliativos é um contexto de sofrimento também para os familiares, haja vista as dificuldades vivenciadas por estes, além dos conflitos e sentimentos que são despertados pelo enfrentamento da doença e o medo da morte. Nesse cenário, a equipe de enfermagem pode atuar como protagonista no elo ente equipe de cuidados paliativos e a unidade de cuidados - paciente/família em prol da promoção do bem-estar biopsicossocioespiritual.

Palavras-chave: Cuidados Paliativos; Família; Cuidadores; Enfermagem Oncológica.

How to cite this article:

Silva RS, Santos RD, Evangelista CLS, Marinho CLA, Lira GG, Andrade MS. Nursing team actions from the perspective of relatives of patients under palliative care. REME – Rev Min Enferm. 2016[cited ____ ____];20:e983. Available from: _____. DOI: 10.5935/1415-2762.20160053

RESUMEN

El objetivo de este estudio fue conocer la percepción de los familiares sobre la actuación del personal de enfermería en la atención a pacientes en cuidados paliativos. Se trata de un estudio cualitativo exploratorio descriptivo llevado a cabo en una clínica de oncología. Participaron 17 familiares cuidadores de pacientes en cuidados paliativos. Los datos se recogieron en febrero y marzo de 2015 en entrevistas, se sometieron al análisis de contenido según el método de análisis de contenido de Bardin y se discutieron de acuerdo a los principios filosóficos de los cuidados paliativos. Se establecieron tres categorías temáticas: sentimientos expresados por la familia cuando el diagnóstico de cáncer en un ente querido afecta la calidad de vida de la familia; prácticas de promoción de la atención que alivian el dolor y el sufrimiento y quimioterapia: momento de dolor y sufrimiento. Se llegó a la conclusión que acompañar a un ser querido en los cuidados paliativos también significa sufrimiento para la familia, teniendo en cuenta las dificultades que vive, además de los conflictos y sentimientos que se desencadenan al enfrentar la enfermedad y del miedo a la muerte. En este escenario, el personal de enfermería podría actuar como enlace entre el equipo de cuidados paliativos y la unidad de cuidados - paciente / familia en la promoción del bienestar biopsicosocioespiritual.

Palabras clave: Cuidados Paliativos; Familia; Cuidadores; Enfermería Oncológica.

INTRODUCTION

The unexpected diagnosis of a loved one's life-limiting disease such as cancer results in serious changes in the family lifestyle. These changes start from discovery of diagnosis, pass through the traumatic treatment possibilities, up to unpredictable outcome of recovery, with a few more days of life, and the moment of death. This situation generates emotional, social and economic conflicts and involves the whole family scenario because, historically, the disease is not seen only as a set of signs and symptoms, but as a cultural, social and moral representation characterized by suffering, distress, despair and expectations enhanced in a variety of possible ways.¹ This is a constant challenge for families who experience or have experienced the communication of the diagnosis of a life-limiting illness in a loved one and the process of taking care of their relative.

In this context, the World Health Organization (WHO)² has sought to include families as part of the care process in the definition of palliative care. The WHO states that such care should follow an interdisciplinary approach and practice aiming to improve the quality of life of terminal patients and their families, seeking to alleviate suffering and pain before the physical, psychosocial, cultural and spiritual problems, in order to provide a dignified death, free from distress and agony. Among its philosophical principles, the WHO reaffirms that the health team should offer a support system to help the family cope with the patient's disease process, as well as with their own grief.

Given this definition, we can infer that families should participate in the decision-making process, strengthening the support, confidence and recognition of their importance in the life of their loved one. Palliative care teams should pay attention to the needs of families, providing them assistance in the best way possible as part of the patient-family care unit.

The care of families is part of the active and comprehensive care to people with life-limiting diseases². As members of palliative care teams, nurses should seek to interact with fami-

lies, so that they may observe how they experience the process of dying of their loved ones. This will aid to analyze and understand how families face and deal with the difficulties arising from the illness and to re-think new strategies to minimize the suffering and to assist the coping.

Integrative review study¹ suggesting five recurring themes identified as the major difficulties that families of patients under palliative care face: control of symptoms and of the burden that falls on the family caregiver; communication process; interpersonal relationships with members of the health team; care management and decision-making process; and inadequate hospital environment.

In this sense, the authors of this study considered how timely is the process of interaction between patients/families and health teams. Considering that, although the provision of care is not restricted to a single profession, Nursing has arguably more opportunities to play a major role in it. This is due to the possibility of transmitting security in both, emotional and technical care. Furthermore, nurses have the privileged possibility of building a bridge between the patient/family and the medical power. The peculiar position of the nursing staff when it comes to proximity with patients gives them this power of mediators. They can encourage patients to fight for the exercise of their autonomy.³

Thus, this study is justified by the difficulty that nurses face to provide care to family members/caregivers during the process of dying and death of terminal patients. It is assumed that turning the applicability of philosophical principles of palliative care visible and practical is reasonable. This is possible from the awakening of a critical view on the nurses' position as members of palliative care teams. The goal of this study was to help providing qualified care to people in terminally process, making it easier for death to occur in a less medicalized manner and as natural as possible. Consequently, the provision of nursing care focused on humanistic, ethical and respectful values for the dignity of dying people is envisaged.

Given the issues abovementioned on families' needs in the context of palliative care, it is expected that this study may incite moments of reflections on how family caregivers of people with life-threatening illnesses and without possibility of cure perceive the care provided by the nursing staff. Furthermore, the study aims that the needs of these families may be understood in order to contribute to the quality of nursing care, making it more resolute, effective, ethical and humanistic as well as encouraging the search for new researches focused on the patient-family care unit.

With the problem presented in mind, the following guiding question was adopted for the study: how do relatives of patients under palliative care assisted in a Oncology service perceive the work of the nursing staff? To elucidate this question, the following objective was established: to know the perception of family members about the nursing teams' performance in the care of patients under palliative care.

MATERIALS AND METHODS

This is an exploratory-descriptive and qualitative study conducted in a Oncology outpatient clinic of a public hospital in Vale do São Francisco, Bahia. This unit is distinguished by providing palliative care for people suffering from oncological diseases. This requires that the nursing staff provide care in the presence of companions, which is usual and necessary. The service does not have an exclusive palliative care team. However, nursing and medical professionals recognize the importance and seek to act within the philosophical principles of palliative care recommended by WHO.

The study participants were randomly selected, and the contact was made using the list of patients registered in the service as reference. Assistance to patients in the ambulatory clinic took place in different moments: weekly, biweekly or monthly, according to clinical indication. Family member/primary caregiver is defined here as the person who routinely accompanied the patient under palliative care during chemotherapy sessions, which was the inclusion criterion for participation in the study. The current definitions of WHO² are adopted for 'patients under palliative care', as already mentioned in the introduction, and for 'patients under end-of-life care'. These definitions set palliative care as "the assistance that the person should receive during the last stage of life, from the moment it is clear that the patient is in a state of progressive and inexorable decline, approaching death"^{4,23} It is noteworthy that this study included only patients under palliative care.

The number of participants was defined according to saturation of answers, considering that this happened at the mo-

ment in which the interaction between the research field and the researcher did not provide new elements to deepen or further theorizing.⁵

This study was evaluated and approved by the CEP/UNEB under nº 870676/2014 respecting the ethical and legal principles for research involving human being, as established in the Resolution nº 466 of 12 December, 2012, of the National Health Council.

The study included 17 relatives identified as primary caregivers of patients under palliative care to cancer undergoing oncological treatment. Data collection occurred during the months of February and March, 2015, using semi-structured interviews which were recorded and addressing the variables of interest: age, sex, relationship, exercise (or not) of the role of primary caregiver and time of accompaniment during the treatment period. To guide the main objective of the research, the following guiding questions were used: which professional usually provides assistance to your relative? What is the frequency of this service? How do you perceive the nurses' care? And the nursing technicians' care? In your view, at what time your relative needs more assistance and monitoring by the nursing staff? Interviews were recorded in a private environment indicated by the institution *locus* of the study, respecting the privacy of the participants.

For the analysis, interviews were transcribed verbatim, outlined, analyzed and discussed. From the data saturation, categories emerged without the need to return to participants, but with the commitment to present the results to the service and to families. In order to preserve the identity of the family members participating in the study, we chose to identify them with the use of the letter "F", to indicate "family member", [F1... F17].

For understanding the interviews, data were processed and analyzed according to the content analysis technique⁶ following the three phases proposed: pre-analysis - floating reading and preparation of data, so that authors could engage in relationships and impressions of the speeches; material exploration - allowing researchers to understand the relationships and impressions of the collected material. Portions of the structures of the contents expressing the object of study were selected and organized in units of meaning. After the identification of the units of meaning, these were orderly grouped, taking into account mutual exclusion, consistency, relevance, objectivity and productivity. Finally, there was the inference step corresponding to the processing and interpretation of results. At this stage, the process of aggregation of themes took place, when the representation of the content was achieved, making it possible to build the thematic categories. These categories were discussed based on the WHO's definition of palliative care and its philosophical principles.²

RESULTS

CHARACTERIZATION OF FAMILY MEMBERS PARTICIPATING IN THE RESEARCH

Among the 17 study participants, 12 were women and five men. They were aged between 21 and 81 years. All identified themselves as primary caregivers and, as for the time they have been accompanying their relative under palliative care, this varied from two months to three years.

THEMATIC CONTENT ANALYSIS

The analysis of the transcribed interviews produced three thematic categories: *feelings expressed by relatives when the loved one's diagnosis of cancer affects the family's quality of life; promoting care practices that relieve pain and suffering; and chemotherapy: a moment of pain and suffering.*

CATEGORY 1 – FEELINGS EXPRESSED BY RELATIVES WHEN THE LOVED ONE'S DIAGNOSIS OF CANCER AFFECTS THE FAMILY'S QUALITY OF LIFE

This category could express how difficult and painful is to witness and to take care of a family member diagnosed with a life-limiting disease without prospect of cure and with few possibilities of treatment which are mostly directed to symptomatic control and possible relief of suffering. The statements show the impact and destructuring experience that families suffer when receiving the diagnosis, along with the whole process of disease that arouses pain and suffering in the family nucleus. The statements indicate that, besides the patient, family members need support and comfort, for them and for their loved one, as illustrated in the following lines:

I felt that I lost stability in life... I don't sleep anymore, I don't eat, lost weight, I don't rest... I was supposed to give him support, sometimes I give, but other times I hide. [...] I feel nervous! I feel sadness, anguish! Seeing this, knowing that we're fighting the problem and are unable to do it (F-5).

I feel a lot of worry and anguish! Especially when they say that there's no more possibility of surgery to help, the problem is more serious than we thought. [...] I thought that chemotherapy, few sessions, could solve it, but actually we've done more than ten sessions and the problem has not been resolved (F-15).

With the diagnosis of a life-limiting illness, various negative feelings and thoughts emerged in the families. They had to face the sorrow of diagnosis and living with such a severe disease.

The release of the bad news is the most impactful for family members. According to the reports, they could not discern the seriousness of the situation before that moment, and, even after being informed of the diagnosis, they keep trying to spare the patient, avoiding to mention the subject, as if he or she did not know what is happening to them.

We felt all very downhearted when we received the diagnosis... We keep praying to God! [...] The doctor told us she had no way, in her presence! Only a miracle of God (F-9).

It was a shock to him and to the whole family when we received the news... All of us felt shattered! We pretend that nothing is happening, to avoid disturbing him further (F-14).

When we got the news, I could not talk to anyone, I just fell into tears, sobbing cry! Today I can open up a bit better, talking about her day to day with us. [...] It was something that we never expected that a family member would ever have to pass through. A real despair! We all panicked, thinking that one day there was already the end (F-17).

CATEGORY 2 – PROMOTING NURSING CARE TO RELIEVE PAIN AND SUFFERING

With advancing of the clinical picture of the life-limiting disease, clinical manifestations appear, whether as result of the progression of a poor prognosis or as a result of side effects of treatments such as chemotherapy. Faced with this typical condition of the disease progression process, family members, even afraid of the unexpected, have observed and signaled the positive performance of the nursing staff, and more precisely have recognized the importance of nurses for them. Thus, these caregivers value the performance of nursing professionals providing care and developing care practices aimed at comforting, with love, affection and attention, in order to alleviate the suffering of patients and their relatives at such a delicate moment of their lives.

I realize that nurses have more affinity with patients. They have more responsibility. She comes and takes care of everyone. She never treated anyone badly and this has helped us very much (F-2).

When I came to the hospital I was very scared, but the nurse helped us and gave us much guidance. She is always cheerful, always happy! She never showed lack of interest, no, on the contrary, she is very hardworking and always gives us the necessary instructions. She gives us excellent assistance! Poor of us if she was not here (F-3).

As a result of chemotherapy, families start to experience constant interaction with the health team. In the reports, family members stressed the importance of active listening and guidance provided by the nurse, especially in times of sorrow before the progression of the disease and the course of treatment. The confidence and reliability that family members develop toward the nursing staff are remarkable. This creates a sense of comfort and support for these caregivers, especially regarding active listening, as evidenced in the following speeches.

Nursing technicians are well helpful, when an emergency happens, as has already happened here, someone had a seizure, they promptly provide care, give the medicines (F-8).

The nurse is very attentive! I like her assistance very much, she knows how to treat patients, she never lets patients down, she is always lifting us up. If he is depressed, she talks to him, telling him it will be all right. She passes over a positive feeling, she gives us support, a shoulder. It is people like this that we need. [...] I am really happy with the service here and especially with the nurse (F-16).

CATEGORY 3 – CHEMOTHERAPY: MOMENT OF PAIN AND SUFFERING

Chemotherapy, in the view of the family, is the most painful and delicate moment of treatment. This is the moment when the consistent presence and assistance from the palliative care team are needed the most. Patients become more vulnerable to pain and discomforts inherent to the use of drugs and because this condition awakens in their family feelings such as worry, anxiety, sadness and, sometimes, even despair.

During chemotherapy, he feels agony in the chest, pain in the knee, arm, sometimes he keeps saying he wants to take it out because he is in agony... This leaves me in agony, I wish I could help in some way, but I can not. It is very painful for me! (F-1).

I feel very sad when I bring him to the chemotherapy because he feels anxious, feels agony, he wants to vomit. It is too much suffering! I don't eat, don't sleep, I just think about it all day long. I get very emotional, because I'm tired and I've become very fragile. It's a hard situation! (F-4)

Such feelings experienced during chemotherapy session anticipate the concern with the next session and ultimately generate new feelings of anxiety and fear. For the study participants, knowing that tomorrow will be a new day and that

they will have to go again and take their loved ones to the clinic to make further chemotherapy sessions is something delicate that causes them concern.

Chemotherapy is a delicate moment, specially for me, as I come with him every time. I wish I would not have to see him like this, suffering. I feel sad, I feel very bitter, I'm praying that this ends soon for us to go home (F-11).

When I come, when I bring him to chemotherapy, I say: Is it tomorrow already? I don't sleep, I don't eat, I keep thinking like, "Oh my God! It's tomorrow"! [Crying] I did not want that for me (F-12).

At the chemotherapy he feels very bad. He's feeling good, but when we mention coming here, he gets bad, because every time he takes it, he feels terrible. He thinks that he comes here to come back even worse. I feel anxious to see him like this, for me it's a nightmare. I feel a lot of anxiety and fear of what may happen (F-13).

DISCUSSION

The results showed families living with a member experiencing the process a life-limiting disease such as cancer pass through disruption of the family dynamics and re-structuring is necessary. The whole process involves feelings and emotions.

The diagnosis of a disease like cancer primarily affects the patient, but the bad news of the consequences also affect families and all those who live with the patient. Throughout this process, a new conformation of the family structure takes place, as the person who was a member of the family and lived in a situation of welfare now passes to the status of a patient with a disease that threatens the continuity of life, in dying process and facing death. The clinical course of the disease implies that the patient will evolve to death. Patient's care cease at this moment, but the family remains in grieving process and requires the continuity of care.⁴

The WHO, when asserting the definition of palliative care and its philosophical principles in 2002, made it clear that there is a need to assist the patient-family unit. This is the essence of full and comprehensive care to the patient in favor of the quality of life and dignity during the dying process and to offer a support system to families to cope with all the suffering generated during the clinical course of the disease and in the mourning period, what may require bereavement counseling.²

Palliative care and its relevance in the health care to terminal patients has evolved over the past decades. In addition to the WHO's definition, a reflection is necessary on the condition in which the provision of palliative care is not limited to the end of life. According to the emerging concept, palliative

care must include patients and their families since the moment of the decisive diagnosis of a serious or life-limiting illness and throughout the course of the disease progression, up to the time of death and beyond that, when it comes to providing support to mourning family members.^{4,7}

WHO's definitions of palliative care and the emerging discussion recognizes that families of patients diagnosed with life-limiting diseases ultimately become ill along with the patient, developing despairing attitudes and experiencing a family claudication process. In this study, this is represented by the lines that convey the feeling of impotence and disruption of the family unit before the diagnosis, and the burden that families begin to take over from that point onwards.

Family claudication is still a subject little discussed in Brazilian studies, but rather frequently mentioned in European publications dealing with patients under palliative care and related families' suffering. Family claudication is defined as the condition of loss of the ability of family members to solve the patient's problems due to the overload of responsibilities. This is specially the case when patients come to depend exclusively on the care of their families. In a given moment, the exhaustion caused by tasks end up causing the caregiver to develop feelings of fear and stress and, the family can not find resources to meet the needs of their loved one.⁸ It is noteworthy that this process can be extended until moments after the patient's death, when the team needs to work the family's grieving process.

For families, following the process of caring for a patient with cancer is a complex experience, filled with suffering and uncertainties. This situation leads to significant changes in the daily lives of these people and eventually affects, somehow, their social and family roles, which significantly increases the need for palliative care to be extended to families.⁹

This call for the recognition of the need to also take care of family members, meeting what is established by the WHO's definition² of palliative care. This is appropriate because, besides emotional commitment, family members also experience physical wear and tear, imposing on them a double overwhelming situation: for themselves and for the other. It is important to recognize that families may not always stand such a challenge and may need to be cared, especially to prevent family claudication.

A study conducted in Spain¹⁰ evaluated the use of Problem Solving Techniques as an intervention to reduce the symptoms of suffering of family caregivers in the prevention of family claudication. There was a statistically significant evidence of improvement of anxiety and depression symptoms among family caregivers. The technique is a low-cost intervention developed by nurses based on a reflection research.

Receiving the diagnosis of a life-limiting illness is a threat to family stability and homeostasis. It brings successive loss of independence and create fears in patients and their families, as

evident in the present reports of caregivers. Patients feel defeated, seeing the proximity of death as a potential phenomenon that can happen at any time.

For families, seeing their loved ones trying to win the battle against a disease like cancer becomes painful and can cause negative symptoms such as insomnia, lack of appetite, depression, fear, among others. Consequently, common sensations to the grieving process also appear, as feelings of anxiety, sadness and anger.¹¹

Restlessness before an unexpected situation such as the diagnosis of a life-limiting disease was evident in the words of caregivers, as mentioned in the category entitled "Feelings expressed by relatives when the loved one's diagnosis of cancer affects the family's quality of life". This inquietude was also evidenced in another study.¹² This study corroborates the present findings when asserting that receiving a diagnosis of cancer of a family member creates agonizing sensations and feelings of anguish and sorrow. This is not only due to the disease itself, but due to the changes that take place in the family environment and the awakening of fear and uncertainty about the outcome of the patient's life history.

Thus, as nursing professionals are every day close to patients and their families, they represent undoubtedly an important tool in the search for an ideal and comprehensive care.^{3,13} In this sense, including the family in the care plan is still a major challenge for palliative care teams.⁷ The team must understand that the patient-family unit is unique and that the provision of care can also rescue the families' quality of life, once lost with the diagnosis of their loved ones. Including family members in health care requires a progressive approximation between palliative care professionals and families. This must include a joint construction of knowledge and decisions, as well as the exchange of information on beliefs, values, rights and knowledge about the responsibilities of each party.¹⁴

In this scenario of suffering of patients and families, our findings demonstrate that caregivers recognize the importance of the nurses' role in the palliative care team. Nurses, according to respondents, have proved to be active in promoting high quality of care, not only regarding technical procedures, but mainly in offering emotional support and attentive listening. Thus, patients and families affirm and value the nursing work, promoting and further expanding their care.

Nursing technicians were not mentioned in the speeches. However, it is inferred that caregivers do not make distinction between nurses and nursing technicians. Only five respondents made this distinction. Three participants reported that nursing technicians spend less time talking to caregivers.

The act of attentive listening is related to the way in which patients and their families are understood. This understanding is reflected in the way the nurse provides its service. Responsibility, concern and respect must be present in each care action, as well as effective and clear information, privacy of patients/families, professional ethics and the own care offered by professionals.

Thus, the importance of the communication process at the interface between nurses – patients – families should not be limited only to the tasks of the act, but should involve listening and feeling as a form of support and of sensitive and humanized listening.¹⁵

Good communication also improves the quality of care provided to patients, besides being an inalienable right and a prerequisite for building a genuine and meaningful relationship between patients, families, nurses and other health professionals.¹⁶ The importance of communication was evident in the interviews when participants signaled that the act of talking and giving information on the procedure to be performed with the patient makes a difference in the care provided by nurses.

Although this study showed a positive influence of the nursing work, more visibility to the practices of nursing professionals is still needed, including in the appreciation as a health team member, considering that at times, family members clearly do not distinguish nurses and nursing technicians.

A study¹⁷ reveals that nurses have not created favorable tools to their professional development and have rarely used communication as a tool for the development of care, for their scientific growth and for the dissemination of knowledge on their role and importance in society. Nurses are usually recognized only for what they do and not for what they are, that is, a component of the interdisciplinary palliative care team.

Communication, whether verbal or non-verbal, is one of the pillars of palliative care, through which bonds are established. Therefore, it is important to emphasize that developing a clear and objective communication process in which families are welcomed, informed, guided and followed is necessary. Quality of health services goes far beyond touching the patient, treating him well and politely.

It is essential that their expectations be met and that their problems be solved in fact, especially regarding the care for their ill family member. Families must be left abreast of decisions, and they must receive explanations on the reasons why a desirable solution has not been achieved, so that the family may feel they are participating in the process.¹⁸

In this sense, meeting the needs of all is a complex task. Nurses need to recognize the environmental influences that surround and limit them¹⁹, This will make them gradually mature and become able to act according to the singularities of individuals, so that they may feel understood, and nurses may recognize their own professional role.

As recommended by WHO, palliative care must be applied early in the course of the disease and in conjunction with other therapies intended to extend the life quality and dignity of patients, such as chemotherapy or radiotherapy. Investigations to better understand and manage distressing clinical complications are also sorely needed.²

The results of the study showed that the use of chemotherapy is expressed as a time of suffering throughout the therapeutic process because it causes psychological and physical distress to both, patients and relatives, because of the suffering generated in their loved ones. Thus, it is clear that family members, although aware of the need for treatment, feel anxious before the side effects caused by chemotherapy.

During the course of chemotherapy, periodic attendance to the hospital is needed. This completely changes the daily life of patients and their families and may cause feelings of sadness, bitterness and despair, besides the feeling burst by the side effects of the use of drugs such as agony, nausea and vomiting, constipation, diarrhea, alopecia, skin patches, fatigue and pain.²⁰

In addition to the abovementioned changes in family dynamics, a prospective cohort study²¹ revealed that there is an association between chemotherapy, even of the palliative type, and the risk of needing intensive care unit care, with possibility of death in the ICU, compromising the quality of life and the dignity of the person at the moment of death.

Thus, it is clear that nursing needs to be attentive to patients and their families during chemotherapy. Besides acting as a facilitator of this process, nursing must seek mechanisms to draw the patient's focus during chemotherapy to other aspects than early identification of side effects. The intention is to soften the suffering of patients as much as possible, in order to improve their self-esteem and the re-signification of their lives, to help them feel content despite the suffering caused by the disease.^{20,22}

Thus, the reality is directly influenced by the way patients develop resilience, how they face obstacles and deal with problems arising from the disease, seeking a reinterpretation of life before the terminal illness. This also happens with families when faced with the situation of having a loved one diagnosed with cancer. They try to reframe the context and avoid family claudication. Thus, resilience becomes an important therapeutic tool in order to adapt to the new and to overcome the situation.²³

In line with the present study, other authors²⁴ have mentioned that periods of chemotherapy generate indisposition, making patients look for ways to minimize suffering, such as sleeping, silence or even watching television. Physical pain is enhanced by invasive procedures, invigorating feelings of apprehension and fear of death.

In this sense, the presence of the family in the hospital setting is essential to alleviate the suffering of patients, as well as to help patients to control their fears and anxieties, and to help them show their feelings and emotions. However, it is up to nurses to encourage the participation of families throughout the care process as a way of appreciating the patients.⁷ This is in line with the definition and philosophical principles of palliative care in the sense that such care should be applied in conjunction with other therapies. The latter are intended to pro-

long the life of patients with quality and dignity. They include chemotherapy or radiotherapy.² Therefore, understanding the needs of patients and their families at the time of chemotherapy will serve as basis to provide humanized care. Respect and dignity must be present in all procedures involving patients and their families, effecting what palliative care actually represents.

FINAL CONSIDERATIONS

The study showed positive aspects regarding the nurses' performance. This was demonstrated through support, care and concern that these professionals impart to family members. The reports of caregivers interviewed are in line with what is recommended by the WHO's definition of palliative care and its philosophical principles. Results show the real need for a service that may consider the exiguity of the care to patients and their families in an honest, dignified and respectful manner, so that they may be supported at this moment that is, in fact, new and unknown in their lives.

Thus, accompanying a family member with cancer under palliative care is a difficult task and may be replete with complications to family members, causing conflicts of feelings triggered by the fear of losing someone so close. Such feelings, and the whole context in which the family is inserted, must be taken into account by the palliative care team.

Before this often despairing situation, the nursing staff can act as a protagonist in the link between the palliative care team and the patient-family unit, for the promotion of bio-psycho-social-spiritual welfare.

The limitations of the study include the fact that the service where the search was conducted, although uses the philosophical principles of palliative care as basis, still does not have an exclusive, trained and specialized team providing such care. However, professionals indeed apply the philosophical principles and develop remedial actions. Although it is acknowledged that palliative actions take place, the absence of care driven by an interdisciplinary and specialized team is notable.

The importance of deepening the subject in new research studies is also outstanding. These may enable nursing professionals to use new strategies to work and take care of families backed on the principle of comprehensiveness and on the philosophy of palliative care, so that family members become appreciated by health teams and, thus, come to feel more comforted and supported.

REFERENCES

1. Robinson J, Gott M, Ingleton C. Patient and family experiences of palliative care in hospital: what do we know? an integrative review. *Palliat Med*. 2014[cited 2015 Feb 13];28(1):18-33. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/23670719>
2. World Health Organization. WHO definition of palliative care. Geneva: WHO; 2015.[cited 2015 Feb 13]. Available from: <http://www.who.int/cancer/palliative/definition/en/>
3. Boemer MR. About palliative care. *Rev Esc Enferm USP*. 2009[cited 2015 Feb 13];43(3):500-1. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0080-62342009000300001
4. Sociedade Brasileira de Geriatria e Gerontologia. Vamos falar de cuidados paliativos. 2015. [cited 2015 Feb 13]. Available from: <http://sbgg.org.br/wp-content/uploads/2014/11/vamos-falar-de-cuidados-paliativos-vers--o-online.pdf>
5. Fontanella BJC, Luchesi BM, Saidel MGB, Ricas J, Turato ER, Melo DG. Amostragem em pesquisas qualitativas: proposta de procedimentos para constatar saturação teórica. *Cad Saúde Pública*. 2011[cited 2015 Feb 13]; 27(2):389-94. Available from: <http://www.scielo.org/pdf/csp/v27n2/20.pdf>
6. Bardin L. Análise de conteúdo. 5ª ed. Lisboa: Edições 70; 2009.
7. Margaret IF, Monika CF, Margaret O. Nursing perspectives on palliative care 2015. *Ann Palliat Med*. 2015[cited 2015 Feb 13];4(3):150-5. Available from: <http://apm.amegroups.com/article/view/7034/7817>
8. Meireles N, Pereira A, Ferreira A, Ferreira S, Vieira E. O Papel parental e a Claudicação familiar: qual a importância do enfermeiro de Família? In: Carvalho JC, Barbieri-Figueiredo MC, Fernandes HI, Vilar AI, Andrade L, Santos MR, et al. Transferibilidade do conhecimento em enfermagem de família. Porto: ESEP; 2012. p. 246-51.
9. Ferreira NML, Dupas G, Costa DB, Sanchez KOL. Câncer e família: compreendendo os significados simbólicos. *Ciênc Cuid Saúde*. 2010[cited 2015 Feb 13];9(2):269-77. Available from: <http://eduem.uem.br/ojs/index.php/CiencCuidSaude/article/viewFile/8749/6076>
10. Ferré-Grau C, Sevilla-Casado M, Lleixà-Fortuño M, Aparicio-Casals MR, Cid-Buena D, Rodero-Sanchez V, et al. Effectiveness of problem-solving technique in caring for family caregivers: a clinical trial study in an urban area of Catalonia (Spain). *J Clin Nurs*. 2014[cited 2015 Feb 13];23(1-2):288-95. Available from: https://www.researchgate.net/publication/259244448_Effectiveness_of_problemsolving_technique_in_caring_for_family_caregivers_A_clinical_trial_study_in_an_urban_area_of_Catalonia_Spain
11. Sales CA, Matos PCB, Mendonça DPR, Marco SS. Cuidar de um familiar com câncer: o impacto no cotidiano de vida do cuidador. *Rev Eletrônica Enferm*. 2010[cited 2015 Feb 13];12(4):616-21. Available from: https://www.fen.ufg.br/fen_revista/v12/n4/v12n4a04.htm
12. Farinhas GV, Wendling MI, Dellazzana-Zanon LL. Impacto psicológico do diagnóstico de câncer na família: um estudo de caso a partir da percepção do cuidador. *Pensando Fam*. 2013[cited 2015 Feb 13];17(2):111-29. Available from: <http://pepsic.bvsalud.org/pdf/penf/v17n2/v17n2a09.pdf>
13. Silva RS, Campos ARC, Pereira A. Caring for the patient in the process of dying at the Intensive Care Unit. *Rev Esc Enferm USP*. 2011[cited 2015 Feb 13];45(3):738-44. Available from: <http://www.revistas.usp.br/reeusp/article/download/40760/44085>
14. Vasconcelos EV, Santana ME, Silva SED. Desafios da enfermagem nos cuidados paliativos: revisão integrativa. *Enferm Foco*. 2012[cited 2015 Feb 13];3(3):127-30. Available from: <http://revista.portalcofen.gov.br/index.php/enfermagem/article/view/296>
15. Camillo SO, Maiorino FT. A importância da escuta no cuidado de enfermagem. *Cogitare Enferm*. 2012[cited 2015 Feb 13];17(3):549-55.
16. Kourkouta L, Papatthanasidou IV. Communication in nursing practice. *Mater Sociomed*. 2014[cited 2015 Feb 13];26(1):65-7. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3990376/>
17. Baggio MA, Erdmann AL. (In)visibilidade do cuidado e da profissão de enfermagem no espaço de relações. *Acta Paul Enferm*. 2010[cited 2015 Feb 13];23(6):745-50. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0103-21002010000600005
18. Andrade CG, Costa SFG, Lopes MEL. Cuidados paliativos: a comunicação como estratégia de cuidado para o paciente em fase terminal. *Ciênc Saúde Coletiva*. 2013[cited 2015 Feb 13];18(9):2523-30. Available from: <http://www.scielo.br/pdf/csc/v18n9/v18n9a06.pdf>

19. Broca PV, Ferreira M A. Equipe de enfermagem e comunicação: contribuições para o cuidado de enfermagem. *Rev Bras Enferm.* 2012[cited 2015 Feb 13];65(1):97-103. Available from: <http://www.scielo.br/pdf/reben/v65n1/14.pdf>
 20. Rodrigues FSS, Polidori MM. Enfrentamento e resiliência de pacientes em tratamento quimioterápico e seus familiares. *Rev Bras Cancerol.* 2012[cited 2015 Feb 13];58(4):619-27. Available from: http://www.inca.gov.br/rbc/n_58/v04/pdf/07-artigo-enfrentamento-resiliencia-pacientes-tratamento-quimioterapico-familiares.pdf
 21. Wright AA, Zhang B, Keating NL, Weeks JC, Prigerson HG. Associations between palliative chemotherapy and adult cancer patients' end of life care and place of death: prospective cohort study. *BMJ.* 2014[cited 2015 Feb 13];348:1219-29. Available from: <http://www.bmj.com/content/348/bmj.g1219>
 22. Fontes CAS, Alvim NAT. Human relations in nursing care towards cancer patients submitted to antineoplastic chemotherapy. *Acta Paul Enferm.* 2008[cited 2015 Feb 13];21(1):77-83. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0103-21002008000100012
 23. Rosenberg AR, Baker KS, Syrjala KL, Back AL, Wolfe J. Promoting resilience among parents and caregivers of children with cancer. *J Palliat Med.* 2013[cited 2015 Feb 13];16(6):645-52. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3719479/>
 24. Cicogna EC, Nascimento LC, Lima RAG. Children and adolescents with cancer: experiences with chemotherapy. *Rev Latino-Am Enferm.* 2010[cited 2015 Feb 13];18(5):864-72. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0104-11692010000500005
-