

PALLIATIVE CARE: THE PERCEPTION OF FAMILY CAREGIVERS OF CANCER PATIENTS¹

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ABSTRACT

The family has a fundamental role in the life of patients facing cancer and represents a structure for the losses and limitations that the disease determines. The aim of the study was to know the perception of family caregivers of terminal cancer patients on palliative care. This is a qualitative study carried out in a palliative care clinic of a referral hospital for the treatment of cancer with eight relatives of hospitalized patients. A semi-structured interview script was used. The interviews were recorded and later transcribed verbatim. The data were analyzed based on the Content Analysis technique in the thematic modality according to Bardin. The Project was approved by the Research Ethics Committee. The results obtained from the analysis of the content pointed to the following categories: Concept of palliative care, Significations attributed to palliative care, Challenges when facing terminality. The experience of family members interviewed made it possible to elucidate the family-patient relationship and to clarify the influence that family caregivers exercise in the process of illness and palliative treatment.

Keywords: Palliative Care. Neoplasms. Perception. Family

INTRODUCTION

In the social environment, cancer is seen as an incurable disease and its diagnosis affects the lives of the families of those affected, causing a series of changes that generate emotional conflicts due to the fear of the experience they will have to live⁽¹⁾. This is because cancer is considered an invasive and complex disease whose course in patients walks towards the prognosis of terminality⁽¹⁾.

Terminality of life is defined as the point when curative therapeutic resources are exhausted and there is no more time and opportunity to do something for the individual, who has no chance of recovering and evolves to death⁽²⁾. As such, this person needs humanized care as well as his family, based on the philosophy of palliative care. The latter consists in improving the quality of life of people who face problems related to a disease outside the possibility of cure⁽³⁾.

The World Health Organization defines palliative care as active and comprehensive care for patients whose disease no longer responds to therapeutic treatment. It is a differentiated care approach that provides a better quality of life for patients and their families through an adequate evaluation for control of pain and other symptoms, as well as psychosocial and spiritual support⁽²⁾.

As families present social, spiritual, physical and psychological demands during the care process of their family member who is ill, they represent units of palliative care⁽⁴⁾. The presence of family members is important when they participate in the care and contribute to the physical and psychological comfort of their ill relative, who can evolve to death at any time or remain for a long time in terminality⁽⁵⁾.

In this sense, families play a fundamental role in the life of patients in facing a disease, being a structure for the losses and limitations that the disease determines⁽⁶⁾. As they provide care, family members

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undergo different changes during the period in which they interact with their relative in palliative care. These changes include social life, responsibilities and uncertainty in the face of the unknown. Thus, they need support to cope with these issues and the challenges surrounding the experience of loss and suffering that they will face⁽⁷⁾.

In view of these considerations, the following question is raised: How do family caregivers of people with cancer understand palliative care? Thus, the relevance of the present study is justified by the importance of improving the professional practice of nurses, as well as the provision of effective and qualified care to terminal cancer patients and their families, because the latter are also an element of care and play a relevant role in the well-being and quality of life of the patient. Another important factor is the small number of studies addressing the theme in the national production.

Thus, the objective of this study was to understand the perception of family caregivers of end stage cancer patients in palliative care.

METHODOLOGY

This is an exploratory, qualitative study carried out in a palliative care clinic of a reference hospital for the treatment of cancer located in the metropolitan region of Recife/PE.

The service has 28 beds for cancer patients in palliative care and counts on a multiprofessional team composed of a doctor, a nurse, a psychologist, a social worker, a physiotherapist and a nutritionist, as well as nursing technicians to perform direct care.

Eight family caregivers of cancer patients hospitalized in the palliative care sector and who met the following inclusion criteria participated in the study: being a family caregiver; being accompanying the person with cancer during hospitalization; being aged 18 years or more. Caregivers who had no degree of kinship with the patient were excluded. For the purposes of this research, a person with blood ties or not was considered to be a family caregiver as long as he or she some kind of kinship with the patient.

Interviews were conducted by an undergraduate nursing student during the months of October and November of 2014, in a private room of the palliative care clinic itself. A semi-structured interview script was used as a data collection tool, with the following guiding questions: In your opinion, what is the meaning of palliative care? What does it mean for you

to have a relative in palliative care? What are the daily challenges of caring for a terminally ill person? What has changed in your life since your family member's received a diagnosis of terminality?

The interviews were previously scheduled and recorded with the consent of the interviewees and later transcribed verbatim. The data were analyzed based on the Content Analysis technique, in the thematic modality according to Bardin, following the steps: quick reading; preparation of the corpus; selection of context units and registration units; coding and categorization⁽⁸⁾.

The interpretation of the material was made after successive readings of the content extracted from the participants' speeches in order to capture relevant information that could go unnoticed. In order to maintain the secrecy of the information and of the interviewees' identity, their speeches were identified by means of numbers and preceded by the letter F, from family member.

The Project was approved by the Research Ethics Committee with the opinion nº 790.205 as established by the National Health Council through Resolution 466 of 12/12/2012, which refers to research involving human beings⁽⁹⁾.

RESULTS AND DISCUSSION

The family members of the study were characterized by gender, age, marital status, schooling and degree of kinship. The female gender predominated, with a mean age of 33.5 years ranging from 18 to 49 years, single marital status, high school education, and the prevailing kinship was daughter.

The results obtained from the content analysis pointed to the following categories: Concept of palliative care; Significations attributed to palliative care; Challenges when facing terminality.

Concept of palliative care

Through the speeches of the study participants it was possible to identify that some present a correct concept about palliative care, as show the following reports:

[...] the care you give the patient when he no longer responds to treatment [...] it is the care to provide a better quality of life to the patient [...](I1)

Palliative care is [...] for him to feel more comfortable, to live better all the time he still has [...] Giving him a

better quality of life, not only for him but also for the relatives who came to make him company [...](I5)

It is the attention that the nurses, the hospital group provide the patient for a better quality of life while they are alive, covering the physical and spiritual side [...](I7)

The concept of palliative care brings an approach of promotion of a better quality of life for patients and families who face problems associated with life-threatening diseases. This is done through the prevention and relief of suffering through prior identification, correct evaluation, treatment of pain and other physical, psychosocial and spiritual problems(10). Palliative treatment is aimed at symptomatic control, with no curative purpose, but rather to promote a quality of life, which must be improved until the end of life(4).

The involvement of the family in palliative care is fundamental because it plays an important role in the formation of the individual and in the maintenance of his quality of life(10). The family member who have the right concept of palliative care will have a better interaction with the patient, contributing to provision of care(4).

However, when questioned about the concept of palliative care, some relatives showed poor knowledge about this type of treatment to given to their relative, as can be seen in the following statements:

He will not be able to go through surgery because his case is very advanced, he can not do any surgery, he has no other treatment [...](I4)

Palliative care is you being caring for that person who is in a certain situation facing the world and you are there on the side of that person, strengthening him, so that he may improve every day more [...](I6)

Although most interviewees showed an adequate knowledge about the concept of palliative care, some still do not have a satisfactory level of understanding, which confirms the need for effective actions in the transmission of this knowledge. In this sense, actions aimed at the support and guidance of family members for the rehabilitation of patients in palliative care in all aspects are necessary to improve their quality of life, maintaining their autonomy and capacity for self-care and family and social interactions⁽¹¹⁾.

Family caregivers need accurate information, without omissions, in a clear and objective way, so

that they can feel more confident and be able to face the experience and prepare to deal with the pain and loss of their relative⁽¹²⁾.

According to the speeches, information on palliative care was obtained through data sources such as magazines and the Internet, as well as through meetings with the multidisciplinary service team. In this context, the performance of nursing in the transmission of knowledge according to the interviewees' narrative is notorious:

I got the information through magazines of great national circulation [...](I1)

[...] participating in the meeting he has here with the companions, the nurses and the social worker [...](I3)

I had this information with the doctor and the nurses here.(I4)

[...] this information I got with the nurse [...](I6)

Through the nurse.(I7)

[...] I started to search in the internet [...] I read and interpreted it in my own way [...](I8)

Access to information helps family members minimize the uncertainties and provides them with a basis for action, since the basic problem they face is insecurity about what to do⁽¹³⁾.

A study shows that family members show a willingness to keep their loved one under their care and this is possible when there is a greater understanding of the subject through information that improves knowledge, bringing greater humanization in care, making the process less painful and leading to a dignified death⁽¹⁴⁾.

As a way to ensure that the family has enough and necessary knowledge to contribute to patient care, it is the responsibility of the multidisciplinary team to pass on the necessary information to the family caregiver in an understandable way. Thus, the nursing team has the greatest contact with patients in hospital treatment and their families, accompanying them in moments of pain and suffering and consequently contributing to their relief and protection⁽²⁾.

It is necessary that family caregivers receive a solid help from health professionals who assist terminal patients to obtain the necessary information about the care that should be provided to the patient through health education actions, in order to guarantee the quality of care(15).

Significations attributed to palliative care

When asked about the meaning of caring for a family member in palliative care, it can be seen in the speeches of the participants that the representation of love and dedication was expressed in the speeches. This shows the family member's desire to be with the patient helping him and trying to soften the suffering of the parent that is in palliative care, as highlighted in the following excerpts:

[...] we need to have the ability to love our neighbor in an unconditional way [...](I1)

[...] it is love, affection, patience.[...](I4)

[...] When you dedicate yourself to that person and see that he is happy because you dedicate yourself, it is very good.[...](I5)

The act of caring means love, an act of caring for the neighbor [...](I8)

Understanding the feelings of users and their families in the face of events such as illness and treatment is relevant for the health team to plan appropriate actions and to provide guidance to such people in line with their needs, taking into account that feelings are not of trivial identification and interpretation⁽¹⁶⁾.

In this sense, the act of caring is based on trust and support, that is, the will to help the loved person triggers in the family members the willingness to play this role never before experienced. When this feeling is accompanied by love, there is no need for external motivation. The demonstration of affection and love in the act of caring can help to alleviate the suffering of the family, and also modifies the fear and emotions, once they become manifestations of respect and solidarity⁽¹⁵⁾.

The family dedicates itself to the care of the patient so that he feels better in emotional and physical sense before the situation in which he is. The greatest concern of the family is to see the improvement of their family member and for that to happen the family does everything in its reach, always with care and attention, as a commitment to be fulfilled. The act of dedication and care is seen as a retribution for what the sick person has done in the past⁽¹⁷⁾.

Some of the relatives mentioned in their reports the sensation of pain during the process of care and faith as way of alleviating suffering and creating hope

for healing. This indicates that spirituality is a significant resource that relatives use to face the period of hospitalization of their relative as a form of spiritual support and strength to face reality:

It is a very great pain for us human beings, we never think that can happen in our family, especially with a loved one [...] You need to have faith in God to believe and believe in healing. And this is the will of God, at least we have a greater comfort.[...](I2)

[...] It is you to believe that God can make a miracle in the life of that person [...](I3)

[...] the pain of seeing a loved relative or a friend that you have like this, leaving [...] we feel shaken when another person leaves, so, you have to be always strong and firm [...] I have to accept the resignations of God, I have to cling to God as much as I want to get well [...](I8)

When the patient is diagnosed that there is no possibility of cure, the family member also suffers the painful impact and may have different reactions, since denial of the condition of his relative up to avoiding communication⁽¹¹⁾.

A study of relatives of cancer patients showed that they experience different types of feelings when they discover that a loved one has the disease, with sadness being the most commonly experienced feeling followed by fear, worry, anguish, shock and hope⁽¹⁸⁾. Such reactions occur by the immediate link that relatives make between cancer and death⁽¹¹⁾.

It is therefore essential to approach spirituality in cases of terminal patients. As nurses are the professionals who assist the individual and his family in daily care, they should know their needs and be able to promote qualified care in this aspect⁽¹⁹⁾.

Seeking support in religiosity through invocation to God is an understandable strategy in a situation of illness because the power attributed to the divine allows the satisfaction of the needs that many relatives can not control⁽¹⁰⁾. Spiritual interventions give hope, direction, and causes positive responses to care by reducing distress, anxiety and depression, substituting them by optimism, resilience and faith⁽²⁰⁾.

Challenges when facing terminality

The caregiver's daily life is surrounded by challenges to be faced constantly. Among these challenges, the participants' speeches have converged on the renunciation that they had to make to take care

of their relative, the financial expenses involved in this care, the psychological self-control necessary for them not to feel weak and fail to provide care, as well as the physical fatigue that surrounds the actions related to care, as can be seen in the following excerpts:

[...] there is a cost involved in caring for the patient and because paying someone is expensive [...]we have to have control of the psychological to be able to take care of the person every day, because if your psychological is not well, you won't be able to do anything [...]the physical issue also weighs heavily, the body tires, the mind tires. And the patient gets tired of you, you get tired of that situation.(11)

[...]I used to live sick too and I left my health problems only to take care of him, to dedicate myself to him alone [...](14)

[...] I do not live my life anymore, I am living my father's life right now [...] my life has been a bit aside [...] because we have to be strong, because if you are not strong you will not pass anything good for the patient [...](15)

The life of the family and of the patient undergoes changes as a result of the diagnosis and treatment of cancer related to a series of problems difficult to understand. A slow and progressive adaptation to a new routine is required, in which the demands and needs begin to make part of everyday family life. Thus, the family needs time to work out their feelings and emotions, outlining new perspectives of life⁽¹⁵⁾.

Family members who are caregivers actively participate in the routine of hospital care to their hospitalized relative. This can generate physical, psychological and social impacts on their own health and, as a consequence, affect the much needed support in the hospitalization process⁽¹⁸⁾.

Study shows that the main challenge encountered by the family in dealing with cancer is not death alone, but mainly the daily monitoring of the person in terminality, which is considered difficult and distressing⁽¹⁷⁾. Family members verbalize difficulties in the process of caring, both technical and relational, and the challenges faced by them are related to lack of information, financial difficulties, emotional conflicts and illness due to routine. The caregiver starts to deal with the suffering of his relative concealing his own pain and needs⁽¹⁷⁾.

Thus, in order to address the challenges and difficulties, caregivers must develop strategies to help

them cope with the difficult time they are experiencing. Therefore, the family group must use tactics to experience the terminality of their loved one. This involves reconstructing family roles and functions, which should be adequate so that everyone can coexist in the best possible way with the diagnosis and treatment. Caregivers must also have desirable elements in the relationship with the patient, including feelings of empathy, love, compassion, and respect for the uniqueness of their relative, maintaining their dignity, privacy, and comfort in the face of limitations⁽²⁰⁾.

Before the diagnosis of terminality, it is natural that the lives of all who are involved in the care of the patient undergo changes in all aspects. According to the statements of the participants of the research, such changes affected their daily routines, their conceptions about their life and their financial situation, as follows:

[...]My routine changed, my life changed, my way of thinking, my friendships, my concept of life changed, my concept of death [...] I think I'll be someone else after that, I hope to become a better person, I hope this is a life lesson that will make me much better and much bigger than I can be, it's a matter of evolution [...] it changed my economic aspect, it changed everything absolutely everything in my life [...](11)

[...]I no longer enjoy going out, hanging out with friends, to have a party and sometimes even in the church itself, we feel so emotionally shaken that we can not have peace within us [...](12)

[...] I have a new concept about life, I give more value to what I think [...](18)

Having a family member with cancer demands a family reorganization to provide care and to compose the role hitherto played by him. Each day of treatment represents a challenge for the family, which changes their routine and requires them to create strategies to overcome the diversities⁽²⁰⁾. Care for end-stage cancer patients demands a great deal of time of dedication from caregivers and this causes them to abdicate much of their daily activities. They have to adapt to a new routine that encompasses the demands and needs of the treatment⁽¹³⁾.

Research with relatives of hospitalized patients showed that caring for a family member whose pathway to terminality is approaching the end is exhausting. It brings financial, physical, psychic and

social expenses. However, the study mention that the caregivers describe this experience as unique and rewarding, one that provides personal and spiritual maturation⁽²⁰⁾.

The disease adds one more event in the context of the patient's and family's life experience. Beyond that, there are a number of other issues that are responsible for leaving family members in a fragile condition, including financial hardship. The lack of financial resources is considered the biggest problem of the family⁽¹⁵⁾.

The number of family members interviewed was considered a limitation of the study because the other companions of patients in the clinic were not related to the patients or refused to participate in the study because they did not know that their relative was in palliative care.

The study made it possible to understand the perception of family caregivers of terminal cancer patients in palliative care and brings substantial contributions to Nursing care practice in order to integrate the family as a unit of care. The experience of the family members interviewed made it possible to elucidate the family-patient relationship and to clarify the influence that the family caregiver exercises in the process of illness and palliative treatment.

The aim of this work was to contribute to deepen the discussions about the topic of palliative care and to understand the real needs of the families during the process of terminality. We suggest further research aimed at nursing professionals in order to identify their perception about the care demands of relatives of terminally ill patients.

FINAL CONSIDERATIONS

CUIDADOS PALIATIVOS: PERCEPÇÃO DE FAMILIARES CUIDADORES DE PESSOAS COM CÂNCER

RESUMO

A família tem papel fundamental junto ao paciente no enfrentamento do câncer, sendo uma estrutura para as perdas e limitações que a doença determina. Objetivou-se compreender a percepção de familiares cuidadores de pessoas com câncer em fase terminal sobre cuidados paliativos. Trata-se de um estudo com abordagem qualitativa que foi realizado em uma clínica de cuidados paliativos de um hospital referência para o tratamento do câncer com oito familiares de pacientes que estavam internados. Foi utilizado um roteiro de entrevista semiestruturado. As entrevistas foram gravadas e posteriormente transcritas na íntegra. Os dados foram analisados com base na técnica de Análise de Conteúdo, modalidade temática segundo Bardin. O Projeto foi aprovado pelo Comitê de Ética em Pesquisa. Os resultados obtidos a partir da análise do conteúdo apontaram para as categorias: Conceito de cuidados paliativos; Significações dos cuidados paliativos; Desafios diante da terminalidade. A percepção dos familiares cuidadores entrevistados possibilitou a compreensão sobre o binômio família-paciente e a influência que o familiar cuidador exerce no processo de adoecimento e acompanhamento da pessoa em tratamento paliativo.

Palavras-chave: Cuidados Paliativos. Neoplasias. Percepção. Família.

CUIDADOS PALIATIVOS: PERCEPCIÓN DE FAMILIARES CUIDADORES DE PERSONAS CON CÁNCER

RESUMEN

La familia tiene un papel fundamental junto al paciente en el enfrentamiento del cáncer siendo una estructura para las pérdidas y limitaciones que la enfermedad determina. El objetivo fue comprender la percepción de familiares cuidadores de personas con cáncer en fase terminal sobre cuidados paliativos. Se trata de un estudio con abordaje cualitativo que se realizó en una clínica de cuidados paliativos de un hospital referencia para el tratamiento del cáncer con ocho familiares de pacientes que estaban internados. Se utilizó un guión de entrevista semiestruturado. Las entrevistas fueron grabadas y posteriormente transcritas en su totalidad. Los datos fueron analizados con base en la técnica de Análisis de Contenido, modalidad temática según Bardin. El Proyecto fue aprobado por el Comité de Ética en Investigación. Los resultados obtenidos a partir del análisis del contenido apuntaron las categorías: Concepto de cuidados paliativos; Significaciones de los cuidados paliativos; Desafíos ante la terminalidad. La percepción de los familiares cuidadores entrevistados permitió la comprensión sobre el binomio familia-paciente y la influencia que el familiar cuidador ejerce en el proceso de enfermedad y acompañamiento de la persona en tratamiento paliativo.

Palabras clave: Cuidados Paliativos. Neoplasias. Percepción. Familia.

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