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Paliative care and...



# **RESEARCH**

Cuidados paliativos e luto: compreensão de médicos residentes

Palliative care and mourning: the understanding of medical residents

Cuidados paliativos y luto: comprensión de médicos residentes

Maria Andréa Fernandes <sup>1</sup>, Indiara Carvalho dos Santos Platel <sup>2</sup>, Solange Fátima Geraldo da Costa <sup>3</sup>, Franklin Santana Santos <sup>4</sup>, Ana Aline Lacet Zaccara <sup>5</sup>, Marcella Costa Souto Duarte <sup>6</sup>

#### **ABSTRACT**

Objective: Investigating the understanding of medical residents about palliative care and mourning. Method: an exploratory study with a qualitative approach, conducted in august 2013 with 18 residents of a university hospital in the city of João Pessoa / Paraiba / Brazil. To enable the collection of data, was used an instrument containing relevant questions to the study objective. The analysis was performed using the Technique of Content Analysis. Results: From the analysis of the empirical material, two categories emerged: "Care that can provide relief of pain and suffering with an emphasis on the quality of life and promotion of dignity" and "Mourning is the feeling of loss on the death of a loved dear". Conclusion: It is considerable that the study demonstrated the understanding of resident physicians about palliative care and mourning, and support further researches on the theme. Descriptors: Palliative care, Mourning, Health professional.

#### **RESUMO**

Objetivo: Investigar a compreensão de médicos residentes acerca dos cuidados paliativos e do luto. Método: estudo exploratório, com abordagem qualitativa, realizado em agosto de 2013 com 18 médicos residentes de um Hospital Universitário localizado no município de João Pessoa/PB/Brasil. Para viabilizar a coleta dos dados, utilizou-se um instrumento contendo questões pertinentes ao objetivo do estudo. A análise foi realizada por meio da Técnica de Análise de Conteúdo. Resultados: da análise do material empírico, emergiram duas categorias: "Cuidados que visam prover o alívio da dor e do sofrimento com ênfase na qualidade de vida e na valorização da dignidade" e "Luto é o sentimento de perda diante da morte de um ente querido". Conclusão: considera-se que o estudo possibilitou evidenciar a compreensão dos médicos residentes sobre os cuidados paliativos e o luto e subsidiar novas investigações a respeito da temática. Descritores: Cuidados paliativos, Luto, Profissional de saúde.

#### **RESUMEN**

Objetivo: Investigar la comprensión de los médicos residentes sobre los cuidados paliativos y el luto. Método: un estudio exploratorio con abordaje cualitativo, realizado en agosto de 2013 con 18 residentes de un hospital universitario de la ciudad de João Pessoa / Paraíba / Brasil. Para habilitar la recopilación de datos, se utilizó un instrumento que contiene preguntas relacionadas con el objetivo del estudio. El análisis se realizó mediante la Técnica de Análisis de Contenido. Resultados: del análisis del material empírico, emergieron dos categorías: "El cuidado que puede proporcionar alivio del dolor y del sufrimiento con un énfasis en la calidad de vida y promover la dignidad" y "El luto es el sentimiento de pérdida por la muerte de un ente querido". Conclusión: Es posible que el estudio demuestra la comprensión de los médicos residentes sobre los cuidados paliativos y el apoyo al luto y la investigación sobre el tema. Descriptores: Cuidados paliativos, Luto, Profesionales de la salud.

¹Nurse. Master's Student of Nursing at the Federal University of Paraíba (UFPB). Specialist in Family Health.Member and Researcher at the Center for Studies and Research in Bioethics - CCS/UFPB.UFPB. Email: m.andreaf@hotmail.com. ²Nurse. Specialist in Urgency and Emergency from FIP/PB.Member of the Center for Study and Research in Bioethics at the Federal University of Paraíba/CCS/UFPB.João Pessoa (PB), Brazil. Email: indiaracs@hotmail.com. ³Nurse. PhD in Nursing from the University of São Paulo - USP.Docent at the Faculty of Graduate and Postgraduate Nursing, Federal University of Paraíba - UFPB.Researcher at the Center for Studies and Research in Bioethics - NEPB/UFPB.João Pessoa. Paraíba. Brazil. UFPB. Email: solangefgc@gmail.com. ⁴Geriatrician Physician.Doctor of Medicine from the Medical School of USP.Postdoc in Psychogeriatry by Karolinska Institute, Sweden.Founding partner of PinusLongævaAdvisory and Consultancy in Health and Education. Email: franklin@saudeeducacao.com.br. ⁵Nurse. Master's Student of Nursing at the Federal University of Paraíba (UFPB). Member and Researcher at the Center for Studies and Research in Bioethics - CCS/UFPB.UFPB. Email: anazaccara@hotmail.com. 6Nurse. Doctorate Student in Nursing from the Federal University of Paraíba (UFPB). Member and Researcher at the Center for Studies and Research in Bioethics - CCS/UFPB.UFPB. Email: marcellasouto@hotmail.com.

## **INTRODUCTION**

he care is an integral part of life, that sets up in a relationship of warmth, responsibility, care and solidarity with others. Under this view, the act of caring should cover actions that respect the dignity, considering the patient in their uniqueness by means of a dynamic relationship involving the humanistic view of being.

With regard to care, specifically with regard to the terminally ill patient, attention and care in their practices have essentially aimed at the biopsychosocial and spiritual well-being of the individual, provide them with a better quality of life and minimize their suffering during the process of terminallity. Therefore, it is particularly important to promote this type of patient the practice of palliative care aimed at terminally ill patient. This type of care is understood as an approach that provides a better quality of life for patients and their families facing a without perspectives pathology of healing and that threaten the continuity of life, through prevention, early assessment and relief of suffering and pain treatment or other physical, psychological, social and spiritual problems, extending the grieving stage. A

Grief is related to an intertwining of reactions to a situation of loss or death of a loved one. It is both a crisis that affects the individual, their family and the wider system of society in which it participates. Being somewhat represented by pain, sadness, loneliness, for those who survive. Usually refers to something inherently negative and life.<sup>5</sup>

It is noteworthy that the palliative team shall be composed of at least a physician, nurse, social worker, pharmacist, physiotherapist, speech therapist, occupational therapist, psychologist, dietician, dentist, among others. Under the perspective of providing support to the patient and family, the entire team must be willing to develop coping strategies to mourning, especially the doctor, because he is the professional involved with the patient and family in the whole context of the attention of a disease terminal.<sup>6</sup>

Therefore, it is important to emphasize that the physician, as a member of the palliative team, seeks to provide guided assistance in palliative philosophy, which does not permit limit or extend the life of the patient, assuring it necessary to relieve the symptoms that lead to suffering care, the prospect for comprehensive care, respecting the patient and his family since receiving the diagnosis of a terminal illness to the elaboration of mourning.

Given the importance of this topic in the field of palliative care, the study has as a guideline the following question: How medical residents include palliative care and bereavement? To answer the proposed question, the present study aims to investigate the understanding of medical residents about palliative care and bereavement.

Given the above, we consider the relevant study, understanding that health professionals can better deal with terminal patients and families who are experiencing grief and situations, from the moment that the doctor recognizes his perception, he can reflect any the context in which human finitude before promoting palliation.

### **METHOD**

This is an exploratory study with a qualitative approach, performed in a teaching hospital in the city of João Pessoa/Paraíba/Brazil. The study population involved resident physicians selected for the proposed research institution. To select the sample, the following criteria were considered: the trader was present at the time of data collection and had availability to participate. Therefore, 18 residents of Medicine of the hospital comprised the study sample.

Data collection occurred in August 2013. To grasp the empirical material, we used a form containing relevant to the purpose of the study comprises the following question questions: How do you understand palliative care and bereavement? Data were analyzed by Technique Content Analysis <sup>7</sup>, which consists of discovering the core of meanings that make up a communication whose presence or frequency have meaning.

The operationalization of the thematic<sup>7</sup> analysis unfolds in three stages: the preanalysis, which includes the choice of documents to be analyzed, the initial resumption of research and development of indicators to guide the final interpretation; exploration of the material, which consists essentially the transformation of raw data, aiming to reach the core of understanding the text, and the treatment and interpretation of the results obtained according to the theoretical framework of the study.

With the analysis of the empirical material, it was possible to construct the following categories: Care that can provide relief of pain and suffering with an emphasis on quality of life and promote the dignity; Grief is the feeling of loss on the death of a loved one, and Grieving is a natural process and a moment that should be respected.

It is noteworthy that during the consent process , the resident doctor invited to participate in the research was clear about the objectives of the study, securing its anonymity , the secrecy of confidential data , the possibility of giving up the research at any stage of the investigation , and consent by signing the consent form, as established by Resolution 466/2012 laying down guidelines and regulatory standards for research involving humans , clarifies the purpose of the research and ensures your anonymity and confidentiality of confidential data.<sup>8</sup>

The project that follows this study was approved by the Research Ethics Committee of the University Hospital Lauro Wanderley (CEP/HULW), registered under protocol n. 184/10. It should explain that to ensure the anonymity of Resident Doctors of the study participants, they were identified by the letter MR, then the numbers one through eighteen. Example: the first doctor who responded to the form was coded as MR1, the second as MR2, and so on.

### **RESULTS E DISCUSSION**

From the data presented, from the discourse of the participants, there was follow-up analysis, in which a careful reading of the responses was performed. To achieve the proposed objectives in this research, the texts have been grouped according to the units of meaning that had, were the themes that approached approximate dimension of palliative care, promoting relief of pain and suffering, and rescuing the dignity of terminally ill patients with the purpose of promoting good quality of life, throughout the process of terminal care and bereavement, which led to the following categories: palliative care aim to provide relief of pain and suffering with an emphasis on quality of life and enhancement of dignity, Grief is the feeling of loss on the death of a loved one and Grieving is a natural process and a moment that should be respected.

Category I - Care that can provide relief of pain and suffering with an emphasis on quality of life and promote the dignity.

The following reports of resident physicians participating in the study point out that this form of care prioritizes the relief of pain and suffering of patients without therapeutic possibility of healing and terminally ill.

Care offered to patients with incurable diseases and who are terminally ill to relieve their pain and suffering [...] (MR10). Palliative care are those measures those improve the quality of life

of terminally ill patients, [...] (MR11).

Relief from suffering and improve the quality of life of patients with incurable disease and end stage. (M R13).

Are measures to relieve pain and suffering to patients with no chance of healing or being terminally treatment. (MR15).

These statements highlight the importance that residents attach to relieve pain and suffering experienced by the patient in the terminal stage. Saunders introduced the concept of total pain as a set of physical, emotional, social and spiritual elements, comprising the painful sensation experienced by the patient care demands that transcend the physical dimension of the body and see the man as a complex being, for its extensive subjective dimension, and inserted into a context of relationships. <sup>9</sup> It is necessary to emphasize that a fundamental principle of palliative care is to promote pain relief.

Meanwhile, therapeutic interventions should, where possible, act in the cause of the pain. For this, some therapies that interfere in the normal physiology and behavior of the individual are required to be little abstruse, less costly and with minimal risk of complications and adverse effects. It is noteworthy that the actions promoted by doctors and other professionals who make up the palliative team configured in some interventions, such as physical contact through touch, effective communication, family involvement in care, the negotiation of special needs, optimal pain control and other symptoms, existential

support, preparing the family for her death, encourage the family to participate in the death and provide support for the grieving. We must point out that the search for a good quality of life for patients under palliative care goes beyond a basic care, ie, demands state and sensations that are as painless as possible as well as the improvement of psychological status, regardless of pathophysiological conditions disease.<sup>10</sup>

In this sense, the World Health Organization (WHO) <sup>4</sup> considers that palliative care can and should be offered as early as possible in the course of any chronic, potentially fatal disease, since defines as those aimed at improving the quality of life, promoting relief of physical symptoms as well as support the needs and spiritual and psychosocial expectations of the patient and his family, from a terminal illness. In the fragments extracted from the testimonies of the participants, research, resident physicians reported that remedy is to provide quality of life to the dying patient, as highlighted in the following reports:

Palliative care aims improving the quality of life and enhances the dignity of patients without therapeutic possibility of cure. (MR2) Are maintained which provide a better quality of life for patients with end-stage up from illness. (MR4) It is a way to assist a terminally ill patient, in order to offer you a better quality of life [...] (MR5) Offer a better quality of life for terminally ill patients. (MR9)

In this speech, resident physicians emphasize the quality of life in promoting palliative care. In this perspective, the professional should single out your action treating the patient as an individual. It is noteworthy that provide care in human finitude can stimulate the search for new meanings and feelings to life, and the professional who provides this care modality shall develop and express new attitudes, valuing other priorities that improve the quality of life of the patient.

The quality of life is defined as the person's perception of their physical, emotional and social, that is, their position in life state, within the values system in which it operates, as well as in relation to their goals, expectations, standards and concerns. Thus, translates to an intimate sense of comfort, well-being or happiness in performing physical, intellectual and mental functions, within the reality of their families, their work and values of the community to which he belongs. 11-12

Importantly, the diagnosis of a terminal illness can negatively impact the perception of well-being, causing changes in their plans. Increasingly, targets to reduce tensions and fears associated with the treatment of patients under palliative care, with an emphasis on obtaining treatment based on minimizing these distressing symptoms are identified. Moreover, throughout the process of finitude, the patient and his family will adapt and learn to live with the fears and limitations. Consequently, the perception of quality of life is modified<sup>2</sup>.

A major goal of palliative care is adding quality of life to days, not days to life. This is a great challenge for clinicians and for the whole team treating terminal patients, since the goal of curing gives rise to the skills of caring, related to suffering, dignity and support.<sup>2-12</sup>

Consequently, palliative care should be valued as a person who has a history in the context of life, not as a prisoner to be a diseased condition. This surely must be the most

important and essential element in palliative care, because, even if he is experiencing an incurable disease, there will always be opportunities for redemption, adaptation and maintenance of the dignity and quality of life.<sup>13</sup>

Another aspect highlighted by some physicians enrolled in the study relates to the enhancement of human dignity in the practice of palliative care, as expressed by the following statements:

Are providing care to terminally ill patients without prognosis, to ensure relief of suffering and dignity. (MR12)

Are the care offered to terminally ill patients or diseases in advanced stages, aiming to give dignity [...] (MR3)

It is care for terminally ill patients in order to relieve the suffering and pain and gives dignity to the patient. (MR8)

Critical care for patients having a decent life. (MR14)

In these speeches, doctors betray that, inevitably, every human life comes to its end, and to ensure that this passage overtaken in a dignified manner with full care, seeking to achieve the lowest possible suffering, is the commitment of those who assist terminally ill patients in the life.

It should be noted that the philosophy of palliative care is a great hope for the proper enforcement of decent care for people who have chronic pain and suffering caused by illness without therapeutic possibilities of cure. These attitudes and procedures of assistance at the end of life, consisting of active and comprehensive care offered to patients with advanced and terminal illness, and their families, giving it the right to die with dignity.<sup>14-15</sup>

In human finitude, it is important to promote support condition that the person can rediscover the meaning of life in this harrowing moment experiences. In such proceedings, the professional conduct palliative care aimed at providing physical, mental, spiritual and social conditions, while preserving as much as possible, functional autonomy.<sup>16</sup>

The physicians participating in the study reported that remedy is intended to restore the dignity and minimize suffering. This understanding is in line with the Brazilian Code of Medical Ethics<sup>17</sup>, which provides that proper medical care to patients at end of life is to give them all palliative care available to avoid suffering from an incurable disease process, respecting their autonomy. The medical impairment, legal and moral, is to act for the benefit of patients and let them fulfill their destiny in peace and with dignity.

Therefore promote a dignified death is possible only when the professional has the ability to offer shelter, protection, aid the patient and family. This aptitude, commonly it is associated with provide adequate listening and caring for those involved in this difficult time. Thus, should be promoted a holistic care, considering the distressing aspects involving a terminal illness. Therefore, it is up to the team, in particular, to the doctor, act sensitively and effectively, clarifying doubts and encouraging positive attitudes during the process of terminally ill and grieving.

#### Category II - Grief is the feeling of loss on the death of a loved one.

We live in a society where that is linked to human finitude must be concealed and even denied. Therefore, it becomes very difficult to live with the pain of losing a loved one,

a sense of loss called mourning, whose manifestations often cannot be experienced or felt. Despite a social position of denial, it is noteworthy that, in the field of Health Science, professionals have been concerned with the terminal ill people and their families, in order to support them in this terminal phase of life. Thus, the statements included in this thematic category illustrate that medical residents perceive grief as a sense of loss of a significant person, as evidenced by these statements:

Grief is the feeling that overcomes us when losing a loved one [...] (MR1).

Sense of loss on the death of another being (MR3).

It is a sense of loss over the death of an individual (MR4).

Grief is a natural reaction of the body to a sense of loss (MR5).

It is the sense of loss [...] (MR14).

[...] Feeling the loss of a loved one (MR15).

Feeling due to a loss of a loved one (MR16).

The testimonies of residents explained mourning as a natural reaction to the loss of someone we love, but it is worth reflecting that the bereaved person needs assistance, host and listening without prejudice to the resumption of life. Once the fight goes beyond human existence in multiple configurations, as the practicalities of palliative care can contribute to the actors of this process may develop loss by death as a natural course of life.

In this assertion, it is considered that normal grief is a healthy response to a stressor, which is the significant loss of a loved one. The ability of the person to experience and express pain, adjust and invest in new bonds sets up a healthy response to the grieving process. However, when feelings provide the denial and repression of pain for the loss, it can trigger pathological mourning, which prevents the person express their sorrows, and, consequently, feel lonely, fragile and depressive.<sup>18</sup>

It is noteworthy that, occasionally, people come out unscathed regret that, although death is common to any living being. However, some aspects can further intensify these losses, such as kinship, age; type of death, the bonds and the internal resources available components that enable or not the elaboration of mourning. The feeling of almost every person who has lost a loved one is always similar: an immense sadness, followed by hopelessness, lethargy, constant crying, that does not alleviate the pain, a longing that invades the heart.

In some reports, presented below, respondents consider that mourning is configured as a feeling of sadness provoked by the loss of a loved one and the family needs a period to accept it and produce it.

It is a necessary period that the family needs to "accept" the death (MR7).

Moments of respect for the feelings of family members (MR9). It is acceptance of death and a passage that every family will spend (MR12).

Feeling sad family members facing a loss that lasts about 60 days (MR18).

These statements denote that promote a palliative care service that integrates not only the patient but also their family, in care on the part of health professionals, such as actions that promote the reduction of fear and anxiety surrounding the difficult time by they are going through. In terminal situations, palliative team should emphasize the

expression of feelings; improve quality of life and facilitating communication. Thus, both the person of finitude as their families benefit from these interventions process, which decreases the likelihood of future psychopathological symptoms such as depression and anxiety, resulting from the loss or grief does not elaborate.<sup>15</sup>

Thus, the family should be informed of the progress of the disease, alerted to possible symptoms develop in the last stage of life, considering the complexity of the experiences of caregivers of terminally ill and relevance of professionals to provide humanized care and to respond to their needs. Therefore, involved in the process feel more comforted when the end time comes.<sup>19</sup>

Grief is one of the areas of study of palliative care involving a form of education for death to patients, families and healthcare professionals, as it provides the daily contact with human finitude, allowing the development of normal grief with sharing feelings and suffering of the losses.

Doctors are culturally trained to think that death is something strange to life and should be avoided at all costs and that its occurrence means a medical failure<sup>20</sup>. With regard to the fact that doctors cannot avoid death or alleviate suffering, reflects onthe experience of their own death and finitude, which can be extremely painful. In this light, these professionals touched by their pain, may be sensitive to the pain of others, ie, in contact with their own pain and loss, are sensitive to the suffering of the people under their care. <sup>19</sup>

A reflection on human finitude leads us to experience the daily losses and to learn with them, recognizing what is essential in this context, the purpose is no longer to preserve the bodily integrity or health, but the dignity and respect to be under hospice care

#### Category III - Grieving is a natural process and a time that must be respected

In this category, it is noticed that the resident doctors emphasize respect for the suffering experienced before the pain of losing a loved one in the final phase of life and it should be addressed with ease, as shown by the following excerpts from the reports:

It is a moment that should be respected and should be considered as a stage of life that cannot be skipped; should be lived so that we can face death more naturally (MR2).

It is a moment that should be respected to the suffering of others as human beings (MR6).

It is a natural feeling at the loss of a loved one and a moment of respect [...] to their relatives and friends (MR8).

Process [...] a natural acceptance of death (MR10).

Grief is a normal period after the death of a person (MR11).

It is a normal state of mind after the loss of loved ones (m R13). Moments of respect to the feelings of others [...] (MR17).

The reports show that for the elaboration of mourning, it is necessary to build an attitude of respect for the feelings of others. It is not suggested that the doctor acts as a relative or a person close to the patient in the final stages of life, but sees that as similar, a being that has yearnings and doubts before a complex and irreversible process and therefore deserves respect, care and monitoring of a professional prepared to support him.

Respect for others is built in its entirety, slowly, seeking a balanced relationship in the whole process of care. Professionals begin to realize that these issues are characterized as a real need that emerges in the work routine. It is imperative to find ways to abide by the wishes of each individual patient and be aware that each person has a story, beliefs and life situations, which means consecrate the individuality of this patient at the time of decisions, making their dignity is respected.<sup>15,21</sup>

Attention to patients and family is decisive in palliative care. The impact of finite process a patient about your family is large and has repercussions on all aspects of your life, from health to economic situations. Grief can absorb pathological problems. Given this reality, bereaved families mention that the existence of efficient communication is configured as the most important element of terminal care. One should also consider that respect for values such as religiosity, culture, care planning with due management of pain and the patient interaction; family and multidisciplinary team are important elements that help prevent pathological mourning. <sup>22</sup>

The feelings of fear, disability, vulnerability and the intrinsic difficulties to loss are the major generators of disorganization that affects mourners<sup>23</sup>. In this approach, is legitimize the testimonials of resident doctors entered this study, when referring to the need to accept death as a natural way of dealing with their grief. So when it reaches the stage of acceptance, family, friends and even the patients themselves are more serene face of the reality of human terminally.

It is worth noting that acceptance is the moment when the pain involved in this scenario of a loved one can express more clearly, feelings, desires, fears and difficulties that surround them. It should be noted that the complexity of this area shows how relevant is the social responsibility of health professionals concerning the needs of the patient and his family. This responsibility, when shared with the multidisciplinary team in palliative care, expands the dimensions of care and considers the needs of the bereaved family holistically.

Throughout the terminal process, you need to give people time to involving the loss and respect their silences and riots. In this situation, you can only help with word of comfort, a touch, a quiet, affordable and sincere presence on affection. Maybe a quiet sense that respects others' pain, a space of unconditional acceptance that streamline emotional life, so that the person does not close and find mechanisms to transform the anguish of loss satisfactory life activities.

The professional cannot be afraid to expose him and engage with the human being assaulted by illness and grief, to share their anxieties, to be an agent of change, to believe that human finitude is only one stage of life. All this involvement is a way of loving, watching and acting. By understanding the essence of each other at the beginning and end of life, caregiver health begins to understand and explain to him the trajectory in the act and art of caring for beings in their existence and in the process of dying with dignity.<sup>24</sup>

It should be mentioned that the covenant, commitment and understanding of what is acceptable and desirable are essentially acceptable, however, above all, the love of man. One must remember that the professional can only reap the results of their care. The attitude of giving the patient will bring you unforgettable and eternal returns.

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## CONCLUSION

Palliative care is presented as a challenge regarding the consolidation of its application of scientific and objective manner on care aimed at terminally ill patients. Its philosophy, as shown in the statements of the participants, emphasizes the importance of promoting a good quality of life by alleviating pain and suffering, and redeems the respect and dignity of the patient, so that he can experience the finite phase life.

The research led us to understand that the resident doctor also recognizes that palliative care, and meet the needs of terminally ill patients who experience, can help their families cope with the imminent end of life situation and all his hard journey, which culminates with death and its painful mourning. For this purpose, physicians should promote palliative care for this family, both the process and the finiteness elaboration of mourning, and will recognize that we need to change the therapeutic approach when it comes to a sick patient with end-stage disease.

Thus, based on the analysis of evidence obtained, it is concluded that it was possible to see the importance and relevance of this study to inform future investigations and contribute to the formation of knowledge in order to broaden the discussion about palliative care, because this is a practice that can provide a less painful evolution and a better quality of life and comfort to terminally ill patients and their families.

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Contact of the corresponding author: Ana Aline Lacet Zaccara Cidade Universitária - João Pessoa - PB - Brasil - CEP: 58051-900 Email: anazaccara@hotmail.com