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RESEARCH

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PALLIATIVE CARE AND TERMINALITY: PATIENT'S PERCEPTION FACING UP TO THE IMPOSSIBILITY OF CURE

Cuidados paliativos e terminalidade: percepção de pacientes diante da impossibilidade de cura

Cuidados paliativos y terminalidad: percepción de pacientes ante la imposibilidad de cura

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ABSTRACT

Objective: The study's main purpose has been to investigate the life perception of critically ill patients undergoing palliative care and facing up to the impossibility of cure. **Methods:** It is an exploratory research with a qualitative approach, which was performed in a Palliative Care Unit of a hospital in Patos city, Paraíba State, Brazil. Ten in-patients of the aforesaid unit have participated of this study. Data collection took place through semi-structured interviews. The empirical material was analyzed using the Content Analysis technique as proposed by Bardin. **Results:** There were two thematic categories, as follows: "Fear and suffering in contemplation of death, powerlessness and appreciation of life" and "Importance of palliative care in the hospital and family support." **Conclusion:** Through this work, it was possible to further understand the terminality process, where such achievement was based on the patients' viewpoints concerning palliative care. Furthermore, it was shown that the family plays a vital role in providing emotional support, then configuring a pillar that complements hospital care, which ensures the maintenance of their quality of life.

Descriptors: Palliative care, Terminal patient, Terminal care, Cancer, Death.

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RESUMO

Objetivo: Investigar a percepção de pacientes terminais em cuidados paliativos diante da impossibilidade de cura. **Métodos:** Trata-se de uma pesquisa exploratória de natureza qualitativa, realizada em uma Unidade de Cuidados Paliativos de um hospital na cidade de Patos, Paraíba, Brasil. Participaram do estudo, dez pacientes internos da referida unidade. Para a coleta dos dados, utilizou-se uma entrevista semiestruturada. O material empírico foi analisado a partir da técnica de Análise de Conteúdo proposta por Bardin. **Resultados:** Evidenciaram-se duas categorias temáticas: “Medo e sofrimento diante da proximidade da morte, sensação de impotência e valorização da vida” e “Importância da assistência paliativa no hospital e apoio familiar.” **Conclusão:** O estudo possibilitou uma melhor compreensão acerca do processo de terminalidade a partir da percepção de pacientes em cuidados paliativos. Revelou também que a família é de grande relevância enquanto suporte emocional, configurando um pilar que complementa a assistência hospitalar o que assegura a manutenção da sua qualidade de vida.

Descritores: Cuidado Paliativo, Paciente Terminal, Assistência Terminal, Câncer, Morte.

RESUMEN

Objetivo: Averiguar la percepción de pacientes terminales en cuidados paliativos frente a la imposibilidad de cura. **Métodos:** Se trata de una investigación exploratoria de naturaleza cualitativa, realizada en la Unidad de Cuidados Paliativos de un hospital en la ciudad de Patos, Paraíba, Brasil. Participaron del estudio diez pacientes internos de la unidad citada. Para la recolección de datos, se utilizó una entrevista semiestructurada. El material empírico fue analizado a partir de la técnica de Análisis de Contenido propuesta por Bardin. **Resultados:** Evidenciaron dos categorías temáticas: “Miedo y sufrimiento ante la proximidad de la muerte, sensación de impotencia y valorización de la vida” y “Importancia de la asistencia paliativa en el hospital y apoyo familiar.” **Conclusión:** El estudio permitió una mejor comprensión del proceso de terminalidade desde la percepción de los pacientes em cuidados paliativos. También reveló que la familia es de gran relevancia como soporte emocional, configurando un pilar que complementa la asistencia hospitalaria, asegurando la mantención de su calidad de vida.

Descriptores: Cuidados paliativos, Paciente terminal, Asistencia Terminal, Câncer, Muerte.

INTRODUCTION

Nowadays, the advance of science and technology in the field of health is notorious. Nonetheless, despite this progress, there are some situations in which the cure of a disease is no longer possible. Given this framework, what can be done to alleviate both suffering and pain of a terminal patient? In this respect, the science of palliative care comes into play, which aims to alleviate pain and suffering, in addition to offering a better quality of life for the patient considered terminal or with an incurable disease from the human standpoint.

According to the World Health Organization (WHO), palliative care aims to improve the quality of life of patients and family members who face problems related to potentially fatal diseases, through the relief of pain and other physical, psychological, social, and spiritual symptoms. This type of care provides support that helps the patient to improve the quality of life from diagnosis to death, in

addition to offering support to the family throughout the disease process until the bereavement phase.¹

Such care is no less important because it is initiated exclusively when medical treatment is no longer effective or when therapeutic resources have been abandoned, but also because they adopt active actions with a specialized approach, with the appropriate use of human care technology, combined with the skills of an interdisciplinary team that will provide humanized assistance based on a holistic view.^{2,3}

Currently, there are established criteria for recommending palliative care: at the time of diagnosis; when the disease is detected at a stage in which the possibility of cure is questionable or when all possibilities of curative treatment or life maintenance have been exhausted, but the disease progresses.⁴

At that moment, information about your real situation is important so that the patient, under these circumstances, does not feel deceived. It is important to inform the stages of treatment, with honesty, being attentive to good communication, a caring look, a touch, a smile with understanding, talking about the spiritual need and how these beliefs influence treatments, are ways to gain the confidence of the patient and the foundation in the structure of palliative care.⁵

It is worth mentioning that the philosophy of palliative care consists of valuing life and recognizing death as a natural event. Palliative care is necessary to ensure that the critically ill patient lives well, despite the proximity of death. Considering this framework, the end of curative therapy should not mean the end of active treatment, but a change of focus with regard to the therapeutic approach.^{2,6}

The terminal patient is the one who presents irreversible disease, whose death seems something close, inevitable and predictable, since all possibilities of rescuing his health conditions have been exhausted.⁷ The terminal phase is considered one of the most difficult moments for the patient, however, when he receives care that reflects his values and desires and helps him to live in the best possible way and to die with dignity in the place they choose - as the philosophy of palliative care suggests - terminality becomes a less distressing process.⁸

Considering the importance of the focus on terminality in the scope of palliative care and the insignificant number of publications in the national literature on the topic, there was an interest in conducting a study that has the following question as its central focus: What is the life perception of critically ill patients undergoing palliative care and facing up to the impossibility of cure?

Bearing the abovementioned in mind, this work meant to investigate the life perception of critically ill patients undergoing palliative care and facing up to the impossibility of cure.

METHODS

It is an exploratory research with a qualitative approach. The study was carried out in a Palliative Care Unit of an Oncology Referral Hospital in *Patos* city, *Paraíba* State, located in the Northeast of Brazil.

The study followed the standards recommended by the international guideline for qualitative research COREQ (Consolidated Criteria for Reporting Qualitative Research), which includes 32 items established by the checklist that consists of specific parts for reporting qualitative studies and excludes generic criteria that are applicable to all types of research reports.⁹

This work counted with a research sample comprised by ten in-patients from the Palliative Care Unit. The anonymity of the participants was assured by their identification with the letter "P" for Patient, followed by the numeral, according to the increasing chronological order of the interviews, for instance, P1 (Patient 1), and so on. For the selection of the sample, the following criteria were adopted: patients in a state of lucidity, conscious and oriented, and who was able to participate in the interview. Severely ill patients who did not have companions were excluded. The number of participants was considered satisfactory, since in qualitative research the numerical criterion is not valued, but the complexity in which the phenomenon occurs.¹⁰

Data collection took place in July 2019, through a semi-structured interview script, with patients in palliative care, contemplating objective and subjective questions. It was performed in the hospital environment at a time when patients were most available, thus avoiding interfering with the assistance provided by the unit team. It was performed in the hospital environment at a time when patients were most available, thus avoiding interfering with the assistance provided by the unit team. The interviews were recorded and transcribed in full by the researchers.

It is worth mentioning that data collection was only started after the research project was approved by the Research Ethics Committee from the *Faculdade Santa Maria*, *Paraíba* State, according to the opinion of No. 1235,456. Therefore, there were fulfilled the formal requirements addressed by the Resolution No. 466/2012, from the National Health Council/Brazilian Ministry of Health, which provides for research involving human beings in force in Brazil, particularly with regard to Informed Consent Form (ICF).¹¹

The empirical material was analyzed qualitatively using the Content Analysis technique as proposed by Bardin.¹² Initially, the interviews were transcribed and organized in order to enable the development of the material analysis steps, following the steps of the technique, which are pre-analysis, exploration, and codification of the material, processing, and interpretation of results, understood as follows: pre-analysis and stage of the organization itself, which allows the initial systematization of ideas for the formulation of hypotheses and objectives for the final data

interpretation.

In this phase, the speed reading and the constitution of the corpus was performed; material exploration - consist of coding, decomposition, and enumeration, considering the rules previously formulated; results processing and data interpretation: foreseeing later inferences, the raw results were processed to be both meaningful and valid.

The pre-analysis process used is shown in **Figure 1**, with the steps of the entire process, relating to the objective of the study, the defined thematic categories, and the rules used for coding the units.

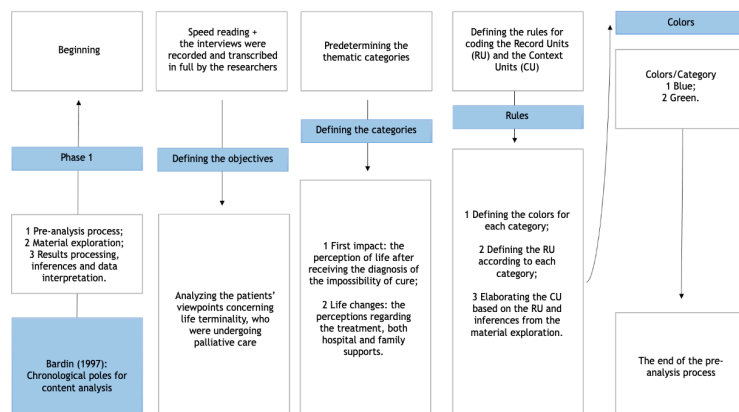


Figure 1: Research pre-analysis flowchart. *Patos* city, *Paraíba* State, Brazil, 2019

Source: Adapted from Silva RS., et al.¹³ 2018.

After obtaining the data, they were consolidated into a Microsoft Excel spreadsheet and organized into a document in the Microsoft Word software, according to questions related to the proposed initial objectives. After speed reading, the material was ordered in separate worksheets according to the thematic pre-categories, following the script of the interviews, constituting the corpus of the research, understood as the set of documents exposed to the analysis for the inferences in the light of the literature pertinent to the addressed topic. Hence, it was possible to identify the following categories: Category 1: Fear and suffering in contemplation of death, powerlessness and appreciation of life; and Category 2: Importance of palliative care in the hospital and family support.

RESULTS AND DISCUSSION

Participants' characterization

Among the ten patients participating in the study, the majority were male and aged over 50 years old. In regard to the marital status, four were married, one was single, two were divorced, and three in common-law marriage. The predominant religion was Catholic.

All research participants were diagnosed with cancer. The types of neoplasms identified were, as follows: three cases of breast, two of lung, two of prostate, one of head and

neck, one of the esophagus, and one of rectum. The time since disease diagnosis and the current health situation of the patient was variable, with a period of less than one year to four participants, from two to five years now being four, and five to ten years now being two.

The following two thematic categories were elaborated from the analysis of the empirical material:

Category 1: Fear and suffering in contemplation of death, powerlessness and appreciation of life

This category was elaborated based on the participants' statements, in which they reported a feeling of fear and suffering experienced after receiving the prognosis of the disease and the proximity of its finitude. In addition to contemplating reports that reveal a feeling of powerlessness and re-signification of life, according to the following citations:

I am afraid of dying now that I know I am no longer treating the disease. (P1)

Too much suffering, but I am prepared for the end. (P2)

The fear of death and not feeling more useful. (P3)

I stopped working and doing other activities. (P4)

I was deprived of many things, starting with work. (P5)

I rethought the little things in life, appreciating my health more [...]. (P6)

My life ended, I was a street vendor and today I cannot even lift a bucket of water. Everything has changed in my life, I stopped doing a lot and now I value life more [...]. (P7)

I stopped doing housework [...] I don't do the things I used to do (P9)

A lot has changed [...]. I was energetic, I worked day and night. Today, I cannot do it anymore [...]. (P10)

Most of the reports presented reflect the perception of these patients in view of the impossibility of cure expressed by the feeling of fear and suffering in contemplation of death, as well as the feeling of powerlessness in relation to their work activities, so that two patients (6 and 7) mentioned, in their speeches, the appreciation of life.

The patients' statements show that as a result of the conditions imposed by the disease, it directly affects their both social and family milieus. Therefore, experiencing this process can mean the deprivation of sociability, in other words, it completely interrupts the normal course of their lives.¹⁴

It is worth mentioning that the experience of death

varies from culture to culture, from family to family and from individual to individual, since the reaction of the idea of approaching death is different from one person to another. The unique human being is and for this reason, each one will manifest and interpret differently from the others.⁵

Over time, death came to be seen as a taboo by society and deaths occur less and less away from the family milieu, due to the resources for the maintenance of life offered by institutions, ceasing to be an inherent event in life. However, it is necessary to maintain and support family processes, combating suffering, anguish, revolt, hopelessness, and fear, as a way to assist the patient in his transcendence.¹⁵

Depending on the context, the experience with situations of illness and death can favor the acceptance of our limits or be an important source of distress,¹⁶ especially when the patient is in palliative care. In this regard, the palliative care patient has a great need to talk about his life, return to his past and reevaluate it in the face of new values, seeking a meaning for his suffering, so that he can live the present in a different way. Serious illness urgently seeks true words and answers to deep existential crises.¹⁷

In the terminal phase, health professionals must provide comprehensive assistance in the final moments of life.¹⁸ In addition to respecting the necessary moment of those who go through the process of dying.¹⁹

Accordingly, the role of the multidisciplinary team in the care of critically ill patients in palliative care is of fundamental importance, since it has, as a central focus, the promotion of humanized care that addresses the biopsychosocial and spiritual aspects of the patient.²⁰

Palliative care seeks to promote the relief of suffering, focusing on the sick person instead of the person's illness, because it rescues and reevaluates interpersonal relationships in the dying process, with effective subsidies such as compassion, empathy, humility and honesty.²¹

Consequently, assisting the patient in the terminally implies attending to other dimensions of the human being, which go beyond the physical ones because it is an experience that involves emotional, affective, and sensory aspects, since these are directly related to the suffering of the patient.²² Hence, the health professional will be able to contribute effectively to alleviate the suffering and mitigate the patient's fear in contemplation of death.

Category 2: Importance of palliative care in the hospital and family support

This category addresses reports from critically ill patients undergoing palliative care, with an emphasis on the relevance of palliative care in the hospital context and the importance of family support to cope with this difficult phase of their lives, as shown in the following statements:

The family helps to relieve the anguish and my fear of being alone. (P1)

This service brings better quality in my life [...] The family helps me by being always present, making me hope for a better life (P3)

Pain relief [...], I prefer to stay in the hospital than at home. Here, I feel good and relieved. My family's support is what keeps me well and helps me through difficult times. (P4)

I believe that the treatment here helps me a lot, so I can have better days [...] My partner was the person who helped me the most with my sister. I don't know what it would be like without them. (P5)

Relieving tiredness helps me to improve my daily life [...] My family is my support on this journey (P6)

My brother does everything for me [...] I feel very happy; if it weren't for him, I'd already died. (P8)

I should have come here sooner; I improved my health a lot. I feel very grateful to my family. Alone, I wouldn't be able to have the life I have today. (P10)

According to the statements mentioned in Category 2, it is perceived the appreciation attributed by patients (3,4, 5, 6 and 10) that concerns the importance of palliative care provided in the hospital environment, since such assistance provides a better quality of life and control of symptoms.

Palliative care directed to hospitalized terminal patients is essential, since this type of care prioritizes the relief of the person's physical, psychological, social and spiritual needs, in addition to integrating the beliefs, values, cultural and religious practices into this care. patients and their families.²³

Based on this understanding, the promotion of palliative care directed at the patient in the final phase of life, in the hospital environment, contributes significantly to improving the quality of life of these patients and their families. This care is conceptualized as an interdisciplinary field of total, active and integral care, given to the patient whose disease no longer responds to curative treatment, from the initial state to the final phase, extending to the family in the period of mourning.²⁴

From this perspective, a study reinforces that palliative care improves the quality of life of patients and their families, who face a life-threatening disease, through appropriate assessment and treatment for the relief of pain and symptoms, in addition to providing psychosocial and spiritual support, so, more than a therapeutic option.²⁵

Palliative care in the terminal process implies ensuring dignity and comfort until the last minute of the patient's life. To accomplish the aforesaid, there needs to be a welcoming environment, like the hospital that helps to minimize pain, relieve anguish and reduce preventable damage, resulting

from a body in progressive decline, allowing a serene crossing.²⁶

Thus, palliative care is essential because it constitutes a care in which humanized measures are adopted aimed at critically ill patients and without possibilities of cure, both in the beginning of the disease and in its final stage. These care aim at individualized care for the patient and his family in the search for control of all symptoms and prevention of suffering, providing comfort, well-being and assistance with physiological needs.

The family, often with emotional, social, economic and cultural embarrassments, is an inseparable binomial, being the responsibility of the nurse and the team, the establishment of partnerships and trust.²⁷ In this respect, most patients participating in the study emphasized the importance of support family and health service to help them cope with the disease process.

Therefore, family support during the hospitalization of the critically ill patient under palliative care is undeniable, since the presence of a family member helps to minimize pain and suffering, reducing anxiety and negative feelings, making him more emotionally stable. In this approach, the family stands out as one of the main emotional supports for the moment of coping with the disease and the final phase of life, configuring a pillar of palliative hospital care.

Hence, it is necessary that the health team that assists the patient is available to deal with the anguish experienced by the family that accompanies the patient throughout the process and that is dedicated to avoid suffering at any cost, which includes, in most sometimes, protecting the patient from any information that may cause sadness and despair. Then, what can be seen are individuals experiencing different times in their lives, members of the same society that resists in admitting the reality of death and, thus, strongly affected by the idea at the time of realizing that nothing can be done to change the course disease. Death is not a hypothesis, but an undisputed truth.²⁸

CONCLUSIONS

Through this work, it was possible to further understand the terminality process, where such achievement was based on the standpoints of in-patients who were undergoing palliative care at a public hospital in the Paraíba State, Brazil. The participants' reports emphatically have shown the difficult trajectory in coping with a disease with no possibility of cure.

Given this reality, the interviewed patients have expressed a feeling of fear and suffering in contemplation of death, a feeling of powerlessness, appreciation and resignification of life. They also underlined the importance of palliative care provided by the hospital chosen for this study, as well as they emphasized the relevance of family support for coping with the disease process, by

providing emotional support, then configuring a pillar that complements hospital care, which ensures the maintenance of their quality of life.

Bearing the aforementioned in mind, it is undeniable the importance of palliative care to promote humanized and comprehensive care to the patient in the final stage of life. It is hoped that this research can support further investigations addressing palliative care towards both the terminal patient and family, since the results obtained here come from a specific group of hospitalized critically ill patients and did not include their families.

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