

PATIENTS AT THE END OF LIFE RECEIVING PALLIATIVE CARE: EXPERIENCES OF A MULTIPROFESSIONAL TEAM

Pacientes sob cuidados paliativos em fase final de vida: vivência de uma equipe multiprofissional

Pacientes en fase final de vida en la atención paliativa: experiencia de un equipo multi profesional

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How to quote this article:

Borba JCQ, Zaccara AAL, Andrade FF, *et al.* Patients at the end of Life Receiving Palliative Care: Experiences of a Multiprofessional Team. *Rev Fun Care Online*.2020. Jan./Dec.; 12:1227-1232. DOI: <http://dx.doi.org/10.9789/2175-5361.rpcfo.v12.9453>

ABSTRACT

Objective: This study investigated the attitudes of multiprofessional team members toward palliative care in the final phase of life. **Methods:** This exploratory study with a qualitative approach was carried out with 15 multiprofessional team members in a philanthropic hospital located in *João Pessoa* city, *Paraíba* State, Brazil. Data were obtained through semi-structured interviews and organized into thematic categories. **Results:** Two categories emerged: “Palliative care in the final phase of life: actions and behaviors of the multiprofessional team members” and “Challenges faced by the multiprofessional team while promoting palliative care in the final phase of life: integration and training”. **Conclusion:** The study participants recognized that greater integration and training facilitate palliative care and improve its quality.

Descriptors: Palliative care, Multiprofessional team, Terminal patient, Death, Terminal illness.

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RESUMO

Objetivo: Investigar a vivência de uma equipe multiprofissional no que concerne a assistência aos pacientes sob cuidados paliativos em fase final de vida. **Método:** trata-se de uma pesquisa exploratória com abordagem qualitativa. O estudo foi realizado em um hospital filantrópico, localizado na cidade de João Pessoa-Paraíba - Brasil, com 15 profissionais de uma equipe multiprofissional. Os depoimentos foram obtidos por meio de entrevista semiestruturada e organizados em categorias temáticas. **Resultados:** da análise do material empírico emergiram duas categorias: I – cuidados paliativos na fase final de vida: ações e condutas da equipe multiprofissional e categoria II – desafios da equipe multiprofissional na promoção dos cuidados paliativos na fase final de vida: integração e capacitação. **Conclusão:** a equipe multiprofissional reconhece que uma maior integração facilite o processo de cuidado e a necessidade de se especializar para o desenvolvimento de competências com vistas à melhoria da qualidade da assistência paliativa.

Descritores: Cuidados paliativos, Equipe multiprofissional, Paciente terminal; Morte, Doença terminal.

RESUMEN

Objetivo: Investigar la experiencia de un equipo multiprofesional con respecto a la asistencia a pacientes bajo cuidados paliativos en la fase final de la vida. **Método:** esta es una investigación exploratoria con un enfoque cualitativo. El estudio se realizó en un hospital filantrópico ubicado en la ciudad de João Pessoa-Paraíba-Brasil, con 15 profesionales de un equipo multiprofesional. Las declaraciones fueron obtenidas a través de entrevistas semiestructuradas y organizadas en categorías temáticas. **Resultados:** del análisis del material empírico surgieron dos categorías: I - cuidados paliativos en la fase final de la vida: acciones y conducta del equipo multiprofesional y categoría II - desafíos del equipo multiprofesional para promover los cuidados paliativos en la fase final de la vida: integración y capacitación. **Conclusión:** el equipo multiprofesional reconoce que una mayor integración facilita el proceso de atención y la necesidad de especializarse en el desarrollo de competencias para mejorar la calidad de los cuidados paliativos.

Descriptor: Cuidados paliativos, Grupo de atención al paciente, Enfermo terminal, Muerte, Enfermedad crítica.

INTRODUCTION

Palliative care is a therapeutic modality that whose primordial attribute is to provide integral care for patients with a life-threatening illness so that their needs can be satisfied. Health care workers should recognize physical, social, emotional, and spiritual symptoms while attempting to deliver this type of care. The concept of palliative care can be extended to people who suffer together with the patient, such as family members, caregivers, and health care workers as they are dedicated to improving terminally ill patients' quality of life.¹ Such a way of providing care values humanization during patient death. In other words, the process of dying can be understood as an opportunity to provide follow-up to care and not as an ending. Therefore, according to this perspective, the terminal patients need to be respected, heard and understood.²

In view of the complexity of care at the end of life, the work of a multiprofessional team is indispensable for palliative care. Dealing with death is difficult for health care workers despite being part of the hospital routine. The reason is that it is an event that involves feelings of

uncertainty, frustrations, discomfort, sadness, anxiety, depression, stress, and impotence.³ Consequently, physicians, nurses, nurse technicians, psychologists, pharmacists, physiotherapists, social workers, nutritionists, dentists, speech therapists, and occupational therapists aid terminal patients. Spiritual advisors also help them according to their religion.¹

Multiprofessional teams are responsible for delivering care for patients whose illness does not respond to cure therapy in the hospital environment as the lack of control of pain or other unpleasant symptoms at home makes these patients need hospitalization for relief and improvement of quality of life.³

A study highlighted that multidisciplinary teams are essential for optimal coordination and clear communication among health care workers. They should employ an approach focusing on patients and family support while paying more attention to psychosocial aspects, quality of life, rights and autonomy of patient.⁴

Considering the relevance of the subject in the context of palliative care, more studies need to be carried out to promote greater dissemination of knowledge in the area. The reason is that there are few publications on palliative care for terminally ill patients from the perspective of a multidisciplinary team. In view of this, the following guiding question was developed: "what are the attitudes of multiprofessional team members toward palliative care in the final phase of life?" Therefore, this study investigated the attitudes of multiprofessional team members toward palliative care in the final phase of life.

METHODS

This is an exploratory study with a qualitative approach, which consists in searching for the singularities and meanings of social reality through beliefs, values, interaction, behavior, and practices.⁵ It was carried out in a philanthropic hospital for patients receiving palliative care located in the municipality of *João Pessoa, Paraíba State, Brazil*.

Health care workers providing palliative care for terminally ill patients were interviewed. Inclusion criteria were permanent employees with at least one year of professional experience. Exclusion criteria were professionals who were on vacation or leave during the data collection period. Thus, 14 multiprofessional team members responsible for providing palliative care composed the study sample: two physicians, four nurses, two social workers, two psychologists, two physiotherapists, and two nutritionists.

The study was approved by the Research Ethics Committee of Hospital Universitário Lauro Wanderley under Legal Opinion No. 731231. Ethical guidelines of Resolution No. 466/12 of the Brazilian Health Council, which regulates research involving human participants,

were followed.

Data collection was carried out from April to May 2019 after the study participants provided written informed consent. Individual interviews were based on a semi-structured interview guide with questions in line with the study objective. A field recording system and field journal were used to record the data. To preserve their anonymity, the study participants were identified with a reference code beginning with the letter I (Interviewee) followed by a number representing the order in which they were interviewed.

It should be noted that the Consolidated criteria for reporting qualitative research (COREQ) were applied to maintain methodological rigor. This tool helps to improve the quality of studies and allows readers to better understand the researchers' conduct toward their designs.⁶

Data were analyzed by means of the thematic content analysis technique,⁷ which allows the description and categorization of the content of the interviews. This technique is composed of three stages: pre-analysis (data operationalization); exploration of the material (determination of categories for an accurate understanding of the record units); and treatment of results, inference, and interpretation (the process of selecting relevant information for analysis based on intuition, reflective analysis, and criticism). This procedure made possible the emergence of two thematic categories: *"Palliative care in the final phase of life: actions and behaviors of the multiprofessional team members"* and *"Challenges faced by the multiprofessional team while promoting palliative care in the final phase of life: integration and training"*.

RESULTS AND DISCUSSION

Characterization of the participants revealed that most of them (10) were females aged from 26 to 58 years. Regarding marital status, six participants were single, seven were married, one was divorced and one was in a common-law marriage. Nine interviewees identified themselves as Catholic. Regarding the length of service in the hospital, the participants had completed between one and 19 years of service.

The collected data were analyzed and grouped into the two categories below.

Palliative care in the final phase of life: actions and behaviors of the multiprofessional team members

The reports in this category highlighted the importance of actions aimed at minimizing pain and other limiting symptoms that cause suffering. Among these actions, following protocols and achieving a good death, particularly one of peace and comfort, were highlighted by the interviewees:

"I conduct various activities when I deliver palliative care, including relief of pain and other symptoms". (I1)

"Palliating pain using medication. Palliating the suffering of patients whose survival rate has been reduced by internal and external factors. [...] I follow the palliative protocol". (I3)

"Relieving the pain using painkillers, aiming at physical and soul well-being and painless death". (I7)

"[...] Working to satisfy the patients' needs, provide comfort for them, relieve their pain, and help them satisfy their desires. Promoting a good death by providing all the care and affection they deserve". (I10)

"Providing attention and care for patients aiming at their better comfort and emotional stability in the face of pain and limitations, considering their medical condition". (I13)

The participants' statements showed that pain is one of the main causes of suffering among terminally ill patients, which compromises their physical and emotional well being.

Pain affecting terminally ill patients rigorously compromises their quality of life since it causes suffering, discomfort, and disabilities. Given its multifactorial origin, pain is also associated with several other aspects such as psychosocial, cultural, philosophical, religious, emotional, and biological issues. In addition, the intensity of these symptoms negatively affects patients' capacity to conduct daily activities most of the time. Therefore, it is fundamental to relieve and monitor pain daily in order for palliative care to be successful.⁸

Some study participants stated that they needed to discuss issues involving spirituality and work on the process of mourning:

"[...] I emphasize the patients' desires until a proper approach to spirituality is adopted". (I1)

"I give psychological support to patients and their relatives from hospitalization to death. I also deal with anticipatory mourning, spirituality, and issues involving the terminal illness and finitude of life". (I9)

"[...] While delivering palliative care, I take care of the physical symptoms and help with the process of mourning and issues involving patients' spirituality". (I11)

The participants' statements evidenced that they were attentive to spiritual issues, which was regarded as an appropriate approach to promote care. One interviewee reported dealing with anticipatory mourning in the face of the finitude of life.

Studies revealed that patients want health care workers to have skills and knowledge to meet their spiritual needs. This strongly contributes to their perception of the quality of care and satisfaction.⁹

Bereavement care is one of the intervention areas of

palliative care. Besides giving support to patients and their relatives, multiprofessional teams must be willing to develop bereavement care interventions by being involved in the process of providing care for patients with a chronic, progressive, and fatal disease. A study¹⁰ reported that it is necessary for health care teams to know the bereavement phases in order to better deal with them.

The ability to communicate is indispensable to multiprofessional work. The participants' statements indicated that verbal and non-verbal communication was viewed as a tool for integral care:

"I make use of communication while I care for patients because I consider it one of the fundamental methods for delivering integral and humanized care [...]. Communication allows the possibility of recognizing and embracing the patients' and their relatives' needs". (I8)

"I make use of communication because it is a fundamental method for delivering integral and humanized care. Communication allows us to recognize and empathically embrace patients' needs. I believe that verbal and non-verbal communication allows patients to participate in decisions and obtain a more dignified treatment". (I12)

"Good communication improves care and the patient feels valued". (I14)

The study participants reported seeking to consider patients' human values and administer a dignified and unique treatment by using communication as the main tool for achieving integral care.

There is strong evidence of the benefits of communicating with patients at the end of their life and their relatives. However, some health care workers still refuse to communicate with them for fear of destroying their hope or harming them.¹¹

A study pointed out that many workers also feel unprepared for or unaccustomed to communicating while they provide palliative care as they do not know what to say in these situations. Another difficulty is the uncertainty about the clinical course of the disease and its prognosis since, which has been impeding discussions about end-of-life care among health care workers.^{11,12}

Thus, it is essential to have interpersonal communication skills, follow appropriate protocols, and use techniques focused on attitudes and procedures that enable dynamic therapy, i.e., the patients' active participation in the process of implementing the care plan and facing the disease. As a result, they can deal with their problems while facing the disease and receiving treatment.¹²

The study results revealed that the multiprofessional team focused on providing palliative care for patients at the end of life by controlling pain stemming from a life-threatening disease. Also, signs and symptoms, such as spiritual discomfort were controlled in order to alleviate suffering and communicate the diagnosis and prognosis of

the disease.

Challenges faced by the multiprofessional team while promoting palliative care in the final phase of life: integration and training

The daily work experiences of the multiprofessional team members and the challenges of providing palliative care through teamwork were identified.

Teamwork is facilitated by the contributions of different professionals and is positively decisive in transforming reality. Most of the study participants pointed out the integrated work of the multiprofessional team:

"The team is integrated and works in an interdisciplinary manner with other teams and in other sectors [...]". (I4)

"The team works in an integrated way, but more knowledge should be gained [...] to offer these patients a better treatment because some professionals still don't know what palliation is". (I5)

"There are good relationships and communication among professionals. I just wish that we could share the conduct more". (I6)

"The team works and in an integrated manner and all of its members act together with the same goal". (I7)

"[...] We have an integrated team, but there are always things we can and should improve. It's a daily challenge.

Our relationship is very good. The team is always attentive to patients receiving palliative care and always tries to satisfy each of their desires in a careful manner". (I12)

"An integrated team, yes! We seek to care for the patient as a whole person. Each member seeks to improve the quality of life of terminal patients and ease their pain and suffering [...]". (I13)

The interviewees pointed out that a dynamic, integrated team can effectively improve the quality of life of patients receiving palliative care at the end of life.

Employing a multiprofessional approach is one of the principles of palliative care. In this way, this type of care must be based on interdisciplinarity, respect for the co-workers' knowledge and particularities, and operative and productive interrelationships. Thus, it is essential to work with cooperation and shared knowledge and practices, especially in decision making, aiming at satisfying the needs of patients receiving palliative care and their relatives.¹³

It should be noted that work relationships among the multiprofessional team members decisively influence palliative care. Some of the interviewees pointed out the need for greater commitment and union, as can be seen below:

"The relationship is smooth but needs to improve on some points regarding teamwork [...], such as the lack of connection among the multidisciplinary team members and the need for a specific project. I would so like our

team members to be more united". (I2)

"The team is multiprofessional, but not all of the professionals work in an integrated way [...]. It is a challenge". (I11)

"Not all team members are united. The relationship is good, but they need to pursue new things and training for the improvement of teamwork". (I14)

"If the members were more united, a better clinical approach could be used to deliver care for patients". (I15)

The study participants' statements showed that there is disagreement about the understanding of teamwork, and the need for an integrated approach is a challenge given the complexity of care.

In order to cover the complexity of human existence, a multiprofessional team is necessary to integrate the sciences or specialties and deal with all dimensions and forms of care, with the aim of easing suffering and pain and improving the quality of life of those involved in this finitude process.¹⁴ It is necessary that health facilities assume a strategic role in the acquisition of knowledge including the philosophy and principles of palliative care. As a result, health care workers can provide this type of care in an integrated manner.

The training process must necessarily contribute to the development of specific skills and abilities related to end-of-life care. In this study, the need for training was also considered a challenge to palliative care. Despite the many challenges evidenced, there is a long and promising path, as can be seen in the following statements:

"With more knowledge and skills gained through training, the team would certainly be more prepared to care for terminal patients". (I3)

"The team works in an integrated way, but there should be more knowledge and training [...] to offer these patients a better treatment because some professionals still don't know what palliation is". (I5)

"We don't have a specialized palliative care unit (PCU) team. I'd like the whole team to have the possibility and opportunity to undergo training in palliative care for improvement purposes considering the current profile of the institution". (I9)

"Within this hospital context, the team members are still adapting themselves to this reality. They're united, but the road is still long. [...] I believe that knowledge acquisition, professional training [...], and daily adjustments will help to promote palliative care". (I10)

The student participants' statements indicated that it is essential to discuss the importance of professional training in the role of promoting comfort to patients receiving palliative care and their relatives.

Being a multi-professional approach, palliative care should be expanded as the disease progresses by creating

more individualized and holistic plans and maintaining scientific knowledge as the anchor of this type of care.

In this sense, it is necessary to greatly disseminate knowledge and education on the philosophy and principles of palliative care among health care professionals. This process should begin during their training and be maintained during professional practice by seeking knowledge or continued education provided by health facilities.¹⁵ A study indicated that palliative care should be delivered and policies aimed at professional training should be implemented to improve this area in Brazil.¹⁶

The study findings showed that the team members faced the challenges of delivering quality palliative care and disseminating knowledge and education on palliative philosophy among health professionals.

It is important to emphasize that the multidisciplinary team members who deliver palliative care share specific knowledge, allowing them to optimize resources and develop a unified, holistic, and integrated treatment plan aimed at caring for patients and supporting their relatives.

CONCLUSIONS

The analysis of the study results allowed us to infer that the multiprofessional team mainly focused on controlling the pain and other symptoms of patients receiving palliative care, satisfying their spiritual needs, and supporting them throughout the process of anticipatory mourning. The ability to communicate is essential for multiprofessional work, which improves the relationships among team members, patients, and their relatives if used effectively.

It was possible to verify the team members needed to demonstrate greater commitment to the improvement of care and discuss the importance and the challenge of undergoing training in palliative care.

This study presents some limitations, including the fact that participants' statements revealed many nuances of palliative care, which were not possible to describe them in detail. In addition, further research needs to be carried out with a higher number of participants from teams at all levels of the Brazilian health care system so that palliative care could be improved.

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Received on: 28/10/2019

Required Reviews: 25/11/2019

Approved on: 07/02/2020

Published on: 17/09/2020

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The authors claim to have no conflict of interest.