

Comfort in the last moments of life: the multidisciplinary team's perception on palliative care

Conforto nos momentos finais da vida: a percepção da equipe multidisciplinar sobre cuidados paliativos

Confort en los momentos finales de la vida: la percepción del equipo multidisciplinaria en cuidados paliativos

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ABSTRACT

Objective: to analyze the perception of professionals of the multidisciplinary team about assistance in palliative care. **Method:** descriptive, qualitative study, developed in October 2017 in a hospital unit specialized in cardiopulmonary diseases located in a capital of Northeastern Brazil. The sample included 15 participants from the multidisciplinary team. Data were collected through semi-structured interviews and submitted to thematic analysis. **Results:** from the analysis, two categories emerged: knowledge of the multidisciplinary team on palliative care and the perception of palliative care practice. The professionals have a still incipient knowledge about what palliative care is and its rogatives, in addition to the need for an effective commitment to the quality of this care. **Conclusion:** Although professionals recognize the need to offer comfort in the final moments of life, knowledge about palliative care is limited and, therefore, professionals perceive dilemmas when dealing with staff, patient and family. **Descriptors:** Palliative care; patient care team; multidisciplinary team; patient comfort.

RESUMO

Objetivo: analisar a percepção dos profissionais da equipe multidisciplinar acerca da assistência em cuidados paliativos. **Método:** estudo descritivo, qualitativo, desenvolvido em outubro de 2017, em hospital especializado em doenças cardiopulmonares situado em uma capital do nordeste brasileiro. O projeto do estudo foi aprovado por Comitê de Ética em Pesquisa. A amostra contou com 15 participantes da equipe multidisciplinar. Os dados foram coletados mediante entrevista semiestruturada e submetidos à análise temática. **Resultados:** da análise, emergiram duas categorias: conhecimento da equipe multidisciplinar sobre cuidados paliativos e a percepção da prática dos cuidados paliativos. Os profissionais possuem um conhecimento ainda incipiente sobre cuidados paliativos e suas prerrogativas, além da necessidade de um comprometimento efetivo para a qualidade desse cuidado. **Conclusão:** apesar de os profissionais reconhecerem a necessidade de oferecer conforto nos momentos finais da vida, o conhecimento acerca do cuidado paliativo é limitado e, por isso, eles vivenciam dilemas ao lidar com equipes, pacientes e familiares. **Descritores:** Cuidados paliativos; equipe de assistência ao paciente; equipe multidisciplinar; conforto do paciente.

RESUMEN

Objetivo: analizar la percepción de los profesionales del equipo multidisciplinario sobre la asistencia en cuidados paliativos. **Método:** estudio descriptivo, cualitativo, desarrollado en octubre de 2017 en una unidad hospitalaria especializada en enfermedades cardiopulmonares ubicada en una capital del noreste de Brasil. La muestra incluyó a 15 participantes del equipo multidisciplinario. Los datos fueron recolectados a través de entrevistas semiestructuradas y sometidos a análisis temático. **Resultados:** del análisis surgieron dos categorías: conocimiento del equipo multidisciplinario sobre cuidados paliativos y la percepción de la práctica de cuidados paliativos. Los profesionales tienen un conocimiento aún incipiente sobre qué son los cuidados paliativos y sus prerrogativas, además de la necesidad de un compromiso efectivo con la calidad de esta atención. **Conclusión:** aunque los profesionales reconocen la necesidad de ofrecer comodidad en los momentos finales de la vida, el conocimiento sobre los cuidados paliativos es limitado y, por lo tanto, los profesionales perciben dilemas al tratar con el personal, el paciente y la familia. **Descriptor:** Cuidados paliativos; equipo de atención al paciente; equipo multidisciplinario; comodidad del paciente.

INTRODUCTION

Palliative care (PC) is an approach that promotes the quality of life for patients outside the possibility of disease-modifying treatment¹. Focused on comfort measures, the PC occurs through the prevention and relief of suffering and assistance to the family in facing difficulties associated with the disease with risk of death². In this sense, early identification, evaluation and treatment of pain and other physical, psychosocial and spiritual adversities are essential in the palliative approach³.

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This perspective of care is directed with the purpose of alleviating existing problems, taking into account the emotional and psychological, in addition to promoting patient autonomy and family support. Therefore, the PC includes in its principles death as a natural process, a health strategy aimed at the integrality of being, the implementation of care to promote comfort and the ratification of the importance of quality of life⁴.

Bearing in mind that the academic preparation of the multidisciplinary team is aimed at saving lives and providing curative care, the approach to finitude remains little explored. In addition to the often incipient training on this topic, it is difficult for the health professional to perceive that their assistance did not give the expected result or the path towards a cure could not be followed, which makes the palliative approach⁵. That being said, reflection and discussion of the palliative approach in hospital environments are challenging.

In view of the importance of the assistance provided by the multidisciplinary team to the patient and their family members who face a life-threatening disease in a hospital and the need for care geared towards comfort based on the theoretical framework of the palliative approach, one wonders *How do health team professionals perceive the assistance in palliative cares?* This study aimed, under this context, to analyze the perception of the professionals of the multidisciplinary team regarding assistance in palliative care.

The proposed discussion on the object of this study may come to highlight the strengths and weaknesses that are related to assistance in the PC, which can support more specific institutional actions for greater knowledge about this care and better strategies for its implementation.

LITERATURE REVIEW

The CP theme has acquired significant relevance in post-contemporary society since the demand for reflection on the right to a dignified death. Discussing on a dignified life is no longer enough; we must also look at our own terminality, ensuring that each human being experiences this existential stage, surrounded by family members and receiving ethical and responsible care. In the concept proposed by the World Health Organization in 2002, quality of life is positioned as a pillar that guides the provided care⁶; in 2018, the same organization, in updating the concept, maintained its focus on quality of life, associated with the need for a team approach to support patients and their caregivers⁷.

The effective participation of the multidisciplinary team gains room at different stages of the implementation of the PC, since its indication, reaching the family conference and consolidating itself with the care and comfort actions themselves. On the other hand, it is not atypical that members of the health team do not recognize in the PC a special care space. Acting in the palliative sphere, concomitant with curative action, is considered to be conflicting and challenging for many health professionals⁸.

The comfort actions that should result from the PCs, necessarily include family members, who undertake their own unique path around mourning the loss of their loved one. It is recommended for the health team professionals to use honest and complete communication, but sensitive to listening to others. Coping with the disease on the part of the patient and family can be achieved through the establishment of quality communication, which results in trust and participation in the decision-making⁹.

METHODOLOGY

This is a descriptive study, with a qualitative approach, developed in October 2017, in a tertiary hospital, specialized in cardiopulmonary diseases, in the city of Fortaleza-Ceará with professionals from the multidisciplinary team of the pulmonology unit that offers treatment to patients with lung cancer, chronic obstructive progressive disease, among others. The workers who work at the unit daily are made up of two nurses, five nursing technicians, two doctors, a physiotherapist, a nutritionist and a social worker.

The team is composed of 35 professionals, however, were considered for inclusion as a participant in the study: Being a professional of the multidisciplinary team working in direct and day-care assistance. The exclusion criteria were applied to team members who were on vacation during the data collection period, as well as those who performed managerial or administrative activities.

For data collection, authorization was requested from the unit's coordination about the need for the professional to be absent from their assistance activities for a brief period. With the consent of the coordinator and the participant for the collection, the professional was sent to a room in the sector with the objective of maintaining their privacy when exposing their perception on the subject at issue. Data were collected using semi-structured interviews, recorded with prior authorization from the participants, whose audio was fully transcribed. The proposal for using the interview script

is that a dialogical and empathic relationship be established between the researcher and the interviewees, which favored an environment conducive to exposing the particular perception of each participant¹⁰.

The interviews were closed when the recurrence of the meanings manifested in the different speeches was acquired, which occurred with 15 interviewed professionals. The used script sought to provide guidance for reaching the objective of the study, without losing the fluidity of questions that arose during the interviews.

In the analytical stage, the emphasis was on the understanding of meanings in the subjects' speech, linked to the context in which they are inserted. The data were transcribed and analyzed from the recorded content, using the thematic analysis method and its analysis criteria: Pre-analysis, material exploration and interpretation¹⁰. In the Pre-Analysis phase, the transcribed material was read for an adequate extraction of the clippings that displayed significant lines for the study's reflection. With the cuts made, it followed with the exploratory phase, where they were organized and reorganized from indicative aspects of similarity, in two analytical categories called: Knowledge of the multidisciplinary team on PC; perception of the multidisciplinary team related to palliative cares.

The data were submitted in textual form and their discussion was carried out with the support of a specialist on PC as its main scope.

Data collection started after submission of the study project to the competent Research Ethics Committee, by issuing a favorable opinion for its execution in 2017, No.2322334. As a way to guarantee the anonymity of the interviewees, the transcribed clippings were identified with an alphanumeric encoding (E: Interviewed; and order number of the interview). The research followed all ethical-legal criteria involving human beings, according to Resolution No. 466/12 of the National Health Council.

RESULTS AND DISCUSSION

Two categories emerged, after analyzing the collected statements: Knowledge on the multidisciplinary team about palliative care and the perception on palliative care practice.

1st Category: Knowledge of the multidisciplinary team on PC

PCs are a therapeutic modality that aims to improve the quality of life of patients, who face life-threatening illnesses, as well as that of their families, where dying with dignity recognizes unconditional intrinsic human values, such as physical comfort, quality of life, autonomy, preparation and interpersonal connection¹¹. Perceptions regarding this care model vary among professionals, producing a diversity of understandings. In the statements below, it is clear that certain professionals were able to elaborate the conception of the CP more closely to that described in the literature, while others described it in a more simplified way.

Here are some testimonials:

Those are cares that seek to bring the terminally ill patient and who no longer has the possibility of healing, comfort, a climate of humanization and integration with the family. (E6)

Palliative care is [...] when the patient has a very advanced disease, everything has been tried and has not been resolved. (E7)

The palliative cares are forms of comforting the patient in their final life instances [...]. (E3)

Such conceptions demonstrate partial knowledge of professionals in PC, expressing a lack of deepening in relation to this theme. This superficial ignorance can cause uncertainty as to when to start the practice of this assistance or even to accept it.

The following testimony compares the PC with something sinful and morally inappropriate, on the part of those who recognize it, and thus, having the relief of suffering is, in some way, compromised.

I still see palliative care as an unknown thing that has been growing in recent years, done in a very timid way, as if I were committing a sin. (E1)

The concern with the implementation of measures aimed at controlling pain symptoms predominates in the speeches in relation to other aspects that the patient may show.

We are applying comfort measures so that the patient should not feel pain, so that they should not be feeling worse than they are already feeling. Relieving pain is very important. (E10)

As previously mentioned, an important point of knowledge of the PC, is the relief of physical pain, as it is the most manifested need, due to the ease of being reported to the professional by the patient, by family members or even perceived by the team, being more accentuated in relation to other aspects that the patient may show.

Pain may be related to a previous invasive procedure or even to a symptom of the current illness and its relief is found in the PC principles, through measures that provide comfort to the patient, since it is essential to promote care so that they may have the best possible quality of life for their clinical condition¹².

It is worth mentioning that the palliative approach must provide humanized care geared to human needs, in all its forms, with a focus on relieving biopsychosocial and spiritual needs, in addition to respect for the patient's values and beliefs, cultural and religious practices of the patient and their relatives¹³.

We seek to work on the psychological aspect of the patient, adjusting moments with the relatives, providing the fulfillment of any request that they make, or even with hospital discharge, whenever possible, so that they may return to their social life and pass their final moments within their family¹¹.

2nd Category: Perception of PC practice

Regarding the professional's perception of the subject, one of the dilemmas found in the study concerns the acceptance of this therapy by the family group.

The respondents demonstrated that in clinical practice, family members also need to work on communication, clarifying the patient's clinical condition and how assistance will develop with the beginning of the PC.

We talked to the patient but forgot to look at the family, [sometimes] the family gets much sicker than the patient. (E15)

Palliative care assistance is the same as for normal patients, what changes is the conduct; we are not going to take the car to a stop, we are not going to do certain procedures that we would do on a patient without palliation. (E4)

When the PC is placed as the therapy of choice, the multiprofessional team must call the family members of this patient to a meeting, whose objective is to inform the clinical picture, expose and clarify what this therapy is and what conduct will be followed. At this moment, communication emerges as a fundamental instrument to boost the relationship of exchanging messages, understanding and exposing feelings and proposals between professionals, the patient and the family¹⁴.

I think that what has to be worked on most are family members, because not everyone accepts or agrees with the prognosis. (E9)

Therefore, when changing the focus of healing assistance to palliation, a challenge perceived by professionals is to deal with family complaints, as not everyone accepts this new approach well, for denying the death process, which is natural in life, or for finding that there is still something to be done to prevent death. In the midst of this process, it is relevant that the feelings and afflictions of family members are taken into account by the team¹⁵.

Often, the physician is in charge of answering questions from patients and family members, since they prescribe medications and procedures in relation to the patient, just as they are expected to have the answers to family questions regarding the disease.

Everyone on a team recognizes that the doctor takes a little bit ahead, don't they? Because the patient is going to ask the doctor, they are not going to ask the physiotherapist what they have, what they do not have, what should be done. (E15)

However, this does not mean that the other professionals on the team are exempt from their responsibilities in relation to informing or answering any doubts that are part of their competence.

A limitation in the literature on the subject is related to how and when to tell the patient, if aware, that procedures aimed at healing will no longer be performed, or that this news be postponed, in order to avoid psychological suffering, as a way of protecting him, by family members¹⁶.

This posture of the family is called in CP as a conspiracy of silence and represents a means of protecting the sick from the news, in others silence comes to camouflage or make up a situation that brings pain, anguish and fears in the face of the unknown or unacceptable reality. Thus, it is essential that patients and family members talk about the problem, favoring the elaboration of a work process that will help to emphasize the quality of life in the last days of existence.^{17,18}

At that moment, the professional must put in practice humanization behaviors with family members and patients, seeking to understand the afflictions, as death is not understood equally by everyone¹⁹. While it is no longer possible to develop hope for a cure, hope for a dignified death can be offered. There is always something more that can be done to comfort the patient and their family, no matter how difficult the situation is, it must be overcome¹⁸.

The patient who is facing life-threatening illness needs to have their special needs met. Sometimes, professionals are led to promote dysthanasia, that is, to use more invasive and high-tech methods, which in an attempt to cure will become unnecessary and ineffective. The wide variety of equipment available to professionals allows intervention on vital variables as an alternative to postpone death at any cost¹.

During the interviews, the professionals report their unpreparedness in dealing with death and the difficulty in implementing the palliative approach within the unit.

I think that in this aspect [palliation] the professional should also be worked [...], I am not used to death. (E10)

The CP is adequate when it avoids invasive measures, without leaving the patient aside, changing the view of care, where the focus is transferred to comfort and no longer to healing²⁰. As for the communication to the patient and the family about not providing new therapies or the withdrawal of those that are in use, the professional should do so emphasizing that if supportive treatment¹⁸.

Such assistance requires a lot from the professionals, not only from the technical-scientific aspect, but also from the human side, which involves knowing how to listen, knowing how to welcome and humanizing in an attempt to supply the demand and offer a contribution that minimizes the suffering of the terminality process, such as the feeling of helplessness, anguish and fear in relation to life²¹.

But according to the following statement, humanization is not for everyone, being put into execution by some and not by others.

The PC practice is not unanimous among the professionals of the multidisciplinary team. There are those who practice this assistance, there are those who avoid it, perhaps because they do not assume the importance of this care or even because they are not satisfied with conducting it (E14).

It is worth mentioning that the proposal of the hospitalization is to stabilize the patient, control symptoms and allow the return to the home, since one of the objectives of the PC is that they may enjoy family life and that death occurs naturally at home. However, it is noted that this is not always possible and death occurs in the hospital environment²².

Following this objective, the Brazilian Ministry of Health has a home care policy, whose modality is to provide care in the patient's home environment, guaranteeing its continuity as an alternative mode for hospitalization, such modality covers the PC, among others, reducing the hospitalization period²³.

However, many deaths occur during the hospital stay, this requires the team to offer comprehensive assistance in an attempt to alleviate such occurrences, in addition to supporting the demands of families that need to be welcomed.

CONCLUSION

Analyzing the testimonies from the professionals of the multidisciplinary team about assistance in PC, two categories emerged - knowledge of the multidisciplinary team on this theme and the perception of the practice in this context.

Professionals recognize the need to offer comfort in the final moments of life, however, knowledge about PC is limited and, therefore, professionals experience dilemmas when dealing with staff, patient and family. Knowing how to deal with a patient affected by a life-threatening illness is complex and difficult.

It is important that the professional identifies with their work, as the human being needs to be continuously cared for, however, this is shown in a special way.

In this sense, it was possible to observe that there are professionals who do not enter the PC and focus only on the technical obligations of the profession, leaving aside the subjective aspects of this assistance proposed, such as the need to strengthen communication, teamwork and a space for discuss terminality. In addition, the difficulty in implementing CP is perceived due to the professionals' inability, since their formation, influenced by the curative health model.

Among the limitations of the study, we highlight the small sample and only one research path, which prevents the generalization of the findings. However, the results express a local reality, serving as support for new articles.

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