
HOSPICE CARE IN A HOSPITAL SETTING: THE EXPERIENCE OF A MULTIDISCIPLINARY TEAM

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ABSTRACT: The objective of this qualitative, descriptive and explanatory study was to identify the experience of a multidisciplinary team in providing hospice care in the hospital setting. The study included six members of a multidisciplinary health team providing palliative care in a university hospital in the South of Brazil. The results indicate that when professionals began providing care to terminal patients, they experienced frustration and a sense of helplessness. The experience, however, enabled them to find new meanings for care delivery, coming to understand death as a natural event of life, and realizing the importance of ensuring quality of life and providing comfort to patients. The participants reported the need to strengthen communication, teamwork, and to create opportunities to discuss terminality. Thus, hospital care should meet the needs of patients receiving hospice care and those of their families, connecting and promoting actions to ensure patients have their suffering relieved and can survive with dignity.

DESCRIPTORS: Patient care team. Palliative care. Hospital care. Terminally ill. Attitude to death.

CUIDADOS PALIATIVOS NA ASSISTÊNCIA HOSPITALAR: A VIVÊNCIA DE UMA EQUIPE MULTIPROFISSIONAL

RESUMO: Trata-se de um estudo qualitativo, exploratório e descritivo, que objetivou conhecer a vivência de uma equipe multiprofissional no cuidado paliativo no contexto hospitalar. Participaram do estudo seis membros de uma equipe multiprofissional de saúde, que atende pacientes em cuidados paliativos, de um Hospital Escola no Sul do Brasil. Identificou-se que os profissionais, ao iniciarem sua trajetória de cuidado na terminalidade, referiram frustração e impotência. Contudo, a experiência fez com que encontrassem novos significados para o cuidado prestado, passando a entender a morte como evento natural da vida e a importância de garantir qualidade de vida e conforto ao paciente. Os participantes relataram a necessidade do fortalecimento da comunicação, do trabalho em equipe e de um espaço para discutirem a terminalidade. Assim, a atenção hospitalar deve atender as necessidades do paciente em cuidados paliativos e família, articulando e promovendo ações que garantam o alívio dos sofrimentos e uma sobrevida digna.

DESCRIPTORIOS: Equipe de assistência ao paciente. Cuidados paliativos. Assistência hospitalar. Paciente terminal. Atitude frente à morte.

LOS CUIDADOS PALIATIVOS EN LA ASISTENCIA HOSPITALARIA: LA VIVENCIA DE UN EQUIPO MULTIPROFESIONAL

RESUMEN: Estudio cualitativo, exploratorio, descriptivo, cuyo objetivo era conocer la experiencia del equipo multiprofesional en la atención de pacientes en cuidados paliativos en el ámbito hospitalario. Participaron del estudio seis integrantes de un equipo multiprofesional de la salud, los cuales proporcionan atención a los pacientes en cuidados paliativos en un Hospital Escuela en el sur de Brasil. Se identificó que los profesionales, al comenzar su trayectoria en la atención a pacientes terminales relataron sentimientos de frustración e impotencia, sin embargo, el tiempo hizo que ellos encontraran nuevos significados a los cuidados prestados. Los profesionales identificaron como puntos a trabajar la necesidad de fortalecer la comunicación, el trabajo en equipo y la creación de un espacio para discutir sobre el proceso por el que pasan los pacientes terminales. Finalmente, la atención hospitalaria debe satisfacer las necesidades de los pacientes en cuidados paliativos y familiares, promoviendo acciones que garanticen el alivio al sufrimiento.

DESCRIPTORIOS: Grupo de atención al paciente. Atención paliativa. Atención hospitalaria. Enfermo terminal. Actitud frente a la muerte.

INTRODUCTION

Hospice care emerged as a therapeutic modality, the philosophy of which is to improve the quality of life of patients and families when facing diseases that threaten life through prevention and relief of physical, psychosocial and spiritual suffering.¹ Traditionally, hospice care is most common in the oncological field. The reason is that even though it can be used in any situation of terminality, 70% of the patients diagnosed with cancer around the world will die due to this disease, which is normally accompanied by suffering.²⁻³

In this context, there are more than 7,000 palliative care services in more than 90 countries. In Brazil, however, there are only 40 specialized services in this therapeutic modality.⁴⁻⁵ Therefore, given the expectation of an increased number of new cases of cancer, meaning approximately 15 million people will be diagnosed with cancer in 2020, the need emerges to expand hospice care.⁶

Initiatives have emerged in Brazil to consolidate palliative care. The National Institute of Cancer (INCA) and the Ministry of Health published in 2001 a manual of palliative care as a way to disseminate information and guide health professionals to provide care to these patients. The established goals include hospice care promoting dignity through therapy focused on the control of symptoms and promotion of quality of life without prolonging or abbreviating survival, while a multidisciplinary approach is essential.⁷

Immediately after the publication of this manual, the National Policy of Oncological Care and the National Program to Provide Pain Care and Palliative Care were established, providing guidelines concerning palliative care to be implemented in all healthcare units. For this reason, the organization of services and multidisciplinary teams are required to care for this clientele.⁸⁻⁹

To palliate is a dimension of healthcare and every professional should know when palliative care is necessary. Ensuring this type of care enables quality care, regardless of whether it is provided at a health facility or at the patient's home.⁴ Cultural aspects, however, associated with social factors, as well as the difficulty involved to provide treatment and manage the patient's symptoms at home, may explain why approximately 70% of deaths occur in hospitals.¹⁰

In this sense, because hospice care involves a complex approach designed to heed all the

patient's and families' dimensions, it requires a multidisciplinary team composed of a nurse, a psychologist, a physician, social worker, pharmacist, nutritionist, physical therapist, speech therapist, occupational therapist, dentist, and spiritual assistant. To achieve this objective, however, it is essential that professionals have a reflective posture in relation to care practices so that hospital facilities have the goal of promoting the human beings' dignity and totality.⁵⁻¹¹

Hospice care mainly implies an interpersonal relationship between the recipient of care and those who provide care, while technical interventions are secondary to the relationship that is established between the multidisciplinary team and patients.² Observing real situations, however, we realize that the process of care delivery has acquired characteristics that are merely technicist and reductionist.¹¹

Hence, given all the aspects relevant for hospice care, which depends on a multidisciplinary approach to produce harmonious and convergent care to individuals, without possibility of a cure, and to their families, the members of the multidisciplinary team need to seek to provide appropriate treatment to these patients. In this sense, it is crucial to recover humanization in the process of dying; that is, death should be seen as part of the process of life.¹²⁻¹³

In this context, teams who provide care to patients in specialized or qualified palliative care services achieve better results controlling physical symptoms such as pain and psychosocial distress and the qualification of these professionals has to be a priority in healthcare services.⁶

The care a multidisciplinary team provides to terminally ill patients in inpatient facilities needs to be discussed and reflected upon. Socioeconomic conditions and the difficulty controlling symptoms at home impede patients from remaining at home and hospitalization is needed. Hence, understanding the team that assists terminal patients in the hospital setting and identifying their conceptions and care practices can contribute to qualifying care and relieving suffering in all its dimensions, valuing human totality.

Therefore, this study is relevant because it gives voice to the professionals who provide such care. The objective of this study is to identify the experience of a multidisciplinary team in providing hospice care in a hospital setting.

METHODOLOGY

Because this study sought to understand the subjectivity of people, we opted for a qualitative, exploratory and descriptive approach.¹⁴ This study was conducted in a clinical hospitalization unit of a university hospital in the South of Brazil. This facility provides care exclusively through the Brazilian Unified Health System (SUS) and in 2007 it received a new license, according to current legislation, to function as a high complexity oncology care unit (UNACON). This study's setting is a hospitalization unit with 24 beds distributed among clinical patients with different pathologies, among them, individuals with neoplasias at different stages. Even though this is not a unit specializing in palliative care, it cares for terminal patients who require this therapy.

To select the study's participants, a work shift was randomly selected in order to preserve the anonymity of professionals. We note that this unit has five teams. Two work in the morning and afternoon and three teams work at night. The selection criteria were: being 18 years old or older, being a member of the unit's multidisciplinary team, and consent to the dissemination of results in scientific media. The study's participants were six professionals working in this unit, one in each field: a nurse, a nutritionist, a psychologist, a social worker, a physical therapist, and an oncologist physician. The participants were identified by fictitious names they chose for themselves.

The professionals were verbally invited to participate in the study. After consenting, the participants signed free and informed consent forms and responded to a semi-structured interview with five open questions addressing their experience with hospice care, barriers and facilitating aspects found in their professional practice and identification data. Interviews took place from September to December 2011 in a room designated for this purpose on the facility's premises. Interviews were digitally recorded and later transcribed verbatim.

Data analysis was composed of three stages: ordering data, compiled from the point the interviews were transcribed to the exhaustive reading of reports, which were organized according to their order of classification in the studied topic. Data were classified and grouped in themes according to the study's objectives based on the authors' theoretical grounding concerning palliative care. The final analysis of data included the researchers' reflections upon the empirical material in order to interpret it.¹⁴

Prior to data collection, the project was submitted to the consideration and approval of the Institutional Review Board at the Medical School, Federal University of Pelotas (Process No. 52/11) according to the standards established by Resolution 196/96, National Council of Health.¹⁵

RESULTS AND DISCUSSION

For the multidisciplinary team, the experience of promoting hospice care in the hospital environment was related to the following: to palliate: control of symptoms and humanized care; experiencing the terminal process and re-signifying care; and challenges faced by the multidisciplinary team in providing palliative care.

To palliate: control of symptoms and humanized care

When the participants described the act of palliating, they mentioned that for the implementation of palliative actions, the multidisciplinary team has to have sensitivity and the ability to identify and care for the diverse dimensions of human suffering.⁴

In this sense, these professionals understood hospice care as the care provided to patients without the possibility of a cure, the purpose of which is to control symptoms. [...] *I understand hospice care is that care that does not aim for a cure, rather seeking to provide quality of life to terminally ill patients, so that the patient experiences no pain, no nausea. It's that care that will not reverse the condition, will not prolong life, but will comfort this patient and his family, as well [...]* (Isabela); [...] *when someone is under hospice care, it is because there's no other way, that is, the person has no chance of a cure; the person will receive care to die better, that is, will have quality of care, relief from pain, comfort [...]* (Amanda); [...] *hospice care is all that care that we demand for a patient who has no chance of a specific cancer treatment, in an attempt to provide greater wellness, improve all the symptoms this patient may experience, alleviate all discomfort. I guess that this is the most appropriate word. And not only in clinical terms but also in terms of emotional, family and social aspects [...]* (Claudia).

The reports show a concern to relieve physical symptoms, especially pain and emotional suffering. No participant, however, reported the spiritual dimension. We also observed the inclusion of the family as part of care and the need to ensure quality of life, which is in agreement with

the philosophy of palliative care defined by the World Health Organization (WHO).

Some of the interviews also showed a concern for the humanization of care delivery, focusing not only on the control of symptoms but also on the need to listen to the patient and family and be in solidarity with them: [...] *I guess that for the patient it is listening, talking, being available, affectionate [...] together with the other team members, try to have an understanding of the situation, try to listen to the difficulties, fears, in this sense, embrace the patient in a time of uncertainty and distress [...] (Isabela); [...] so, if we had a hospital where you could - now, we have a TV room, but if we had a place where you could take this patient and take a walk. Even if it was small place, a garden, so he could see the sunshine, you know? It would be better [...]* (Aline).

It is crucial that the health team devises strategies to control physical symptoms for end-of-life care to be excellent, but it also needs to value the patients' need to alleviate emotional and spiritual distress that may emerge in this situation. The importance of humanized care and the establishment of an empathic relationship among health workers and patients and families in order to promote improved quality of life were also highlighted.

Palliative care imposes a challenge on health professionals to provide care with scientific competence without, however, forgetting to value the human being.¹⁶ For these needs to be met and for care to be integral, it is essential that the health team establishes empathic interpersonal relationships, listening and being sensitive to the patients' needs, more than possessing technical skills to diagnose and treat. These patients expect for the relationship with health professionals to be based on compassion, respect and empathy to help them during the disease process, valuing their experience.⁵⁻¹⁷

The report of Isabela shows her experience with a terminal patient who refused to undergo a surgical procedure. [...] *I guess they have to have autonomy, have to be respected. For instance, in the case of a patient [...] who am I to obligate her to undergo this surgery? I did what I could, I talked to her, the physician talked to her [...] informed the ambulance, and everything was arranged for her. What depended on the health team was done. Now it's her decision. I guess we have to respect that. It's her right [...]* (Isabela).

We perceive in this testimony that the patient's right to autonomy is acknowledged by the professional team. We understand that palliative

actions should aim not only to control symptoms but also lead to valorization of the patient-staff relationship and strengthen trust between the patient and the health staff. For that, one should respect these people's rights to autonomy, one of the principles that permeate palliative care.

Multidisciplinary work is necessary for hospice care intended to recover ethical and human values such as individual autonomy.¹⁸ Care should be shared and cancer patients deserve all grace and respect from professionals. Helping them in all the phases of the process implies providing guidance without forcing, showing them the benefits and disadvantages of each treatment in an intelligible manner according to their level of understanding.¹²

Experiencing the process of terminality and re-signifying care

When the professionals mentioned aspects related to the routine work performed in the process of terminality, we noted that at the beginning, the professionals found it difficult to accept the finitude of life, as well as the impossibility of halting the progress of the disease. The experience, however, changed their conceptions and new meanings emerged for the care provided.

The beginning of the work was marked, according to the professionals, by suffering and distress, coupled with the fact that they felt helplessness and were frustrated with death: [...] *so, in the beginning, it was really hard, the first times, when I came here and started to treat cancer patients. It was really distressing; we suffer a lot in the beginning [...]. And you acknowledge that there is nothing you can do. It's dealing with impotence [...]* (Amanda); [...] *at the beginning it was really hard; it was really difficult to accept it, you know [...]* we are not prepared to see a patient who is beyond our knowledge. It seems that it is us who are failing, who lack the knowledge to provide care at the end of life [...] *it's really frustrating to have knowledge, resources, and get to a point when everything you do, nothing works. It gets to a point when it goes beyond your desire; there's a limitation [...]* (Ana).

When they encountered the reality of death and the impossibility of avoiding it, because it is a natural outcome of advanced diseases such as cancer, the workers started to question their professional practice, their technical and scientific knowledge to assist dying patients. This process, however, serves to trigger discussions concerning the need and importance of hospice care in inpatient facilities.

Death is still seen by many health professionals as a failure, as incapacity or incompetence, since they were trained to fight it.¹⁹ Terminality is related to feelings such as fear, impotence, sorrow, depression, guilt, failure and error.²⁰

Work routines, however, led the professionals to reflect upon their practice and find new meanings for the care they provide, accepting the terminality of life and the importance of their work so that patients and families can cope with such a moment: [...] *in the beginning, you know, working with terminally ill patients [...]. But then, I could see that the role the team plays is essential. It provides support in a time that is so difficult [...]. So, the work itself, the daily practice itself, and many families helped me to deal with this situation [...]* (Isabela); [...] *and have to be strong, to be professional. But as a person, how can you feel useful, you know? As a professional, you're playing your role [...]* (Amanda); [...] *and one of the situations in which we can provide help and feel gratified, I guess that it is when there is some important symptom that we are able to control [...]* (Claudia).

In this sense, the interviewees, after coming to understand their limitations and acknowledge death as a natural event, re-signified their experience of care, such that the possibility to help patients and families is seen as gratifying and the multidisciplinary work is seen as essential.

The work of health professionals leads to many forms of stress but also enables moments of satisfaction.⁴ The multidisciplinary team that provides care to terminally ill patients often times becomes involved with and sensitized to the patient and his/her family and usually share in their suffering.²¹

In this way, they create opportunities for an interpersonal relationship that enables the establishment of bonds with patients and families, as the participants report: [...] *the bonds are strong and when death occurs, the feeling is also strong [...]* (Ana); [...] *so, as I knew she was really bad, I delayed my arrival, but it seems she waited [...]. It seems she waited for us to arrive to [die]. And we were involved, both the social worker and me, up to the end of the afternoon, with the family [...]* (Carolina); [...] *it's not as manipulating a medication, 2ml of something, 5ml of another, no, it's a person, it's a human being, who will exchange part of herself with me. So, of course that we establish bonds [...]* (Isabela).

The health professionals in hospital facilities tend to spend most of their time providing care directly to patients and families and when

they face situations of distress, such as a process of terminality, they share their anguish and difficulties, as an important moment of exchanging in their lives. In this sense, the act of providing care to patients at the end of life, and to families, enables the establishment of bonds, and is decisive to concretizing the humanization of care delivery.

Challenges faced by the multidisciplinary team in providing palliative care

Among the challenges faced by the multidisciplinary team in providing care were conflicts and the need to qualify the team to identify the difficulties dealing with the terminal process. [...] *sometimes it becomes tiresome, also for the employees. Because not everyone is prepared to dealing with this type of patient. Because when you have a specific service for it, it's different. Because the person working in such a service knows she will work with this kind of situation. It's not our case here [...]* (Aline); [...] *there is also a fear of being held responsible for something. You have to be ok and say: from now on there is nothing else to do, [...]* *but you have to be sure and careful to do it right. It has to be very, very well prepared, professionally qualified, multidisciplinary [...]* (Amanda).

The reports show a lack of preparedness on the part of the health staff in hospital care in relation to end-of-life palliative care and this fact triggers situations filled with internal conflict. At other times, we perceive the difficulty the multidisciplinary team has reaching a consensus in relation to procedures that possibly do not benefit patients: [...] *but another difficulty is that, sometimes, you have to use means that you don't want to use. For instance, a patient who you know will not benefit from a procedure due to his condition, at that time, such as the passage of a probe, the administration of feeding tube. But you see yourself obligated to do it, due to the insistence of the family itself or of other colleagues. I don't know, but I see the patient's interest, you know? Because he knows that it won't help much; it's only additional suffering [...]* (Carolina).

The work relationship among the multidisciplinary team plays a decisive role in the care provided to terminal patients. Hence, it is essential that the team's decisions enable the democratic participation of its members and, moreover, the participation of the patient him/herself, giving priority to the patient's comfort and quality of life.

A concern with being able to feed the patient who suffers from advanced cancer is reason for discussion among health professionals. Nutri-

tional care, however, should be integrated with global cancer care and contribute to quality of life.²³ The cohesion of the team in relation to goals and plans is essential and contributes to a relationship of trust with patients and families.²¹

In regard to the communication of the team with patients: [...] *so, I guess that the thing that works for us here, at the hospital, to care for patients, is to try to have better communication and work as a team, you know? And try to provide better care [...]* (Aline); [...] *sometimes, there is no communication, no information on what has changed; it depends on the teams [...]* (Ana).

The ability to communicate, essential for multidisciplinary work, is seen by the interviewees as a strategy to overcome difficulties and limitations. This reasoning can also be observed in another study in which excellent communication and respect among members contribute to the quality of care delivery.²⁴

The participants mentioned the importance of qualification for the good practice of end-of-life palliative care: [...] *maybe one alternative would be to offer people more educational programs on palliative care, for them to understand more about it. If there was a course in college, I guess it'd help a lot [...]* (Amanda); [...] *really, the coverage of this field in the health field is very deficient, in all the aspects of knowledge and practice, too [...]* *but the patients are living longer and they increasingly need palliative care. And I guess that demand only tends to grow, and we have to get better informed. It'd be great if all the multidisciplinary teams could participate in updated training programs, but programs taught by people who are really prepared to talk to us about it [...]* (Claudia).

The training process should necessarily contribute to the development of specific competencies and skills related to end-of-life care.¹⁹ Specialized or trained health professionals achieve better results in the control of physical symptoms, such as pain and emotional suffering and their qualification should be a priority in the health services.⁶

The interviewees reinforced the importance of meetings or groups addressing this subject and also a change of culture in health care focusing on spirituality: [...] *this is a need everyone has, to discuss terminality, discuss the professionals' own spirituality [...]* *so, it's a lack of discussion, I guess that terminality in relation not only to scientific knowledge, but as a part of spirituality, the professional being prepared to understand death, I don't know if you can understand it, but to really discuss it [...]* (Ana); [...] *each one has her own idea, and maybe because of religion and*

the beliefs of each. But I think it's important to listen to different opinions, such as a pastor, someone from another religion, or some other person more familiar with it, to give us some basis [...] (Claudia); [...] *death is a difficult thing, it's something we are not prepared to deal with [...]* *it's a cultural thing and it's not because we are health workers, the fact that we work here, that we take all our feelings and throw them away. It's something that needs to be worked inside. I think it's important for people who have a more developed spirituality, who manage to deal with this spiritual aspect. I guess it helps [...]* (Isabela).

The reports show the need to discuss issues that involve the spirituality of professionals, also as a way to qualify the care delivered to terminally ill patients. At this time, the participants did not mention spiritual issues as relief for suffering, as recommended by WHO. Perhaps this fact is related to limited discussion on the subject.

Therefore, assisting terminally ill patients mobilizes emotions in the members of the health staff because death becomes part of their routine, generating conflicts and the need to reflect, which requires support. The establishment of groups enabling professionals to express distress and difficulties related to the process of death and dying promotes comfort and contributes to the care provided to these patients. Hence, it is necessary to pay attention to the needs of health workers, as they are human beings providing care and also need to be cared for themselves. This condition seems to influence their disposition to care for others, especially to provide care focused on spiritual aspects.²⁵⁻²⁶ Health service managers should identify the weaknesses of institutions and prioritize strategies that enable understanding these aspects,²⁷ especially in terms of qualifying professionals and ensuring excellent scientific and humanized palliative care to patients and families who face the process of terminality.

FINAL CONSIDERATIONS

The multidisciplinary team providing hospice care to patients in the hospital setting comprises care in diverse forms, and their experience is built and rebuilt during their professional lives. Therefore, it is evident that when the professionals initiate this trajectory, they feel frustrated and impotent in relation to death, as it is seen as their failure since they are trained to fight it.

The work routine and experience acquired in the delivery of care to terminal patients require

these professionals to reflect upon their practices and conceptions and, thus, re-signify the care they provide. This enables them to understand death as a natural event of life and the importance of the multidisciplinary team to ensuring quality of life and comfort to patients and families. This fact is linked to the establishment of bonds between the study participants and their patients so that they share the moments of difficulty and distress, which cause suffering in these workers but, primarily, provide satisfaction and professional achievement, promoting humanized care that is essential to end-of-life palliative actions.

In this process the professionals identified weaknesses and challenges imposed on the multidisciplinary team, such as the need to qualify communication and teamwork. They perceive training and education in the service provided in hospital facilities as a tool to achieve objectives, since most palliative actions in this facility is focused on home care.

Finally, we note that care provided to patients with advanced cancer, who depend on hospice care, needs to be reflected upon and strengthened in hospital facilities because social and physical conditions such as difficulty in controlling symptoms, lack of a caregiver, as well as a lack of beds and homecare teams, often impede patients from remaining at home and hospitalization is required.

When such a need arises, the multidisciplinary team should be able to meet the patient's need in an integral and humanized manner, linking and promoting actions to ensure dignified survival and appropriate control of physical, emotional and spiritual symptoms as recommended by the philosophy of palliative care, understanding patients and families in their subjectivity and complexity, as someone for whom there is much to be done.

We expect that this study will contribute to the improvement of knowledge and especially will draw the attention of managers and professionals to the need to promote continuous education for the health team, providing end-of-life palliative care to patients in the hospital setting, as well as promoting the need to discuss emotional and spiritual aspects, in order to qualify care delivery.

The limitations of this study are related to the number of participants and the study setting, which is a single hospital. Even though these factors impede generalization of the data, the results are valid because they reflect similar conditions verified

in larger studies. Hence, complementary studies addressing the subject are needed. There is also a need for studies addressing palliative care in hospital facilities in order to discuss and research more deeply this modality of care provided to inpatients.

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