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Death And Grief in Palliative Care: Health Professionals' Experience

Morte e Luto em Cuidados Paliativos: Vivência de Profissionais de Saúde

Muerte y Luto en Cuidados Paliativos: La Experiencia de los Profesionales de la Salud

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ABSTRACT

Objective: The study's main goal has been to analyze the discourse of nursing professionals regarding the care of patients under palliative care at the time of death and family mourning. **Methods:** It is a qualitative field research carried out with ten nursing professionals working at two hospitals in the City of *João Pessoa, Paraíba* State. **Results:** The analysis of the statements given by the professionals has shown their understanding of death, revealing their feelings and palliative care at the time of death, in addition to identifying family care and the difficulties faced during the grieving process. **Conclusion:** The research has shown gaps concerning the knowledge of nursing professionals concerning the process of death and mourning, making clear the need for encouraging the implementation of continuing education in palliative care services, focused on education to better understand the meaning of death in its dimensions, and to provide both patient and family with better assistance concerning the exercise of their profession.

Descriptors: Palliative care, Hospice care, Death, Mourning, Health professional.

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RESUMO

Objetivo: Analisar o discurso de profissionais da Saúde sobre o cuidar de pacientes em cuidados paliativos, no momento da morte e luto da família. **Métodos:** Pesquisa de campo, de natureza qualitativa, realizada com dez profissionais da Saúde, vinculados a dois hospitais de João Pessoa, Paraíba. **Resultados:** A análise dos depoimentos mostra a compreensão dos profissionais sobre a morte, revela os sentimentos e a assistência paliativa deles no momento da morte, além de identificar a assistência à família e as dificuldades enfrentadas no momento do luto. **Conclusão:** O estudo evidenciou lacunas no conhecimento dos profissionais da Saúde acerca do processo de morte e de luto, sendo necessário incentivar a implementação da educação continuada nos serviços de cuidados paliativos, voltada à educação para a morte, a fim de que eles possam compreender as dimensões desta e proporcionar ao paciente e família melhor assistência no exercício de sua profissão.

Descritores: Cuidados paliativos, Cuidados paliativos na terminalidade da vida, Morte, Luto, Profissionais da saúde.

RESUMEN

Objetivo: El propósito del estudio ha sido analizar el discurso de profesionales de la salud sobre con respecto al cuidado de los pacientes bajo cuidados paliativos al momento de la muerte y duelo de la familia. Métodos: Es una investigación de campo cualitativa realizada con diez profesionales de enfermería vinculados a dos hospitales en la ciudad de João Pessoa, estado de Paraíba. Resultados: El análisis de las declaraciones muestra la comprensión de los profisionales sobre la muerte, revela los sentimientos y la asistencia paliativa de los mismos en el momento de la muerte de los pacientes, además de identificar la asistencia a la familia y las dificultades enfrentadas en el momento del duelo. Conclusión: El estudio evidenció lagunas en el conocimiento de los profesionales de la salud acerca del proceso de muerte y duelo, siendo necesario incentivar la implementación de la educación continuada en los servicios de cuidados paliativos, volteada a la educación para la muerte, a fin de que ellos puedan comprender las dimensiones de esta y proporcionar al paciente y familia mejor asistencia en el ejercicio de su profesión.

Descriptores: Cuidados paliativos, Cuidados paliativos al final de la vida, Muerte, Aflicción, Profissional de la salud.

INTRODUCTION

Palliative care is a type of care that provides an increase in the quality of life of patients with life-threatening diseases, promoting the prevention and relief of suffering at the physical, psychological, emotional, and spiritual levels.[1]

Study[2] states that health professionals, in general, do not feel prepared to deal with this situation. It highlights some reasons such as advanced stages of diseases such as cancer - considered to be feared situations because they are linked to physical and moral suffering, mutilation and death. Other reasons for this unpreparedness[3] are the lack of disciplines that, during the training of health professionals, address death in the context of palliative care, and the lack of permanent education in healthy work environments, which prevents the process of reflection on the subject to overcome the difficulties. On the other hand, the literature is still scarce, presenting gaps in knowledge about the theme[2]. All of this contributes to the ignorance of these professionals concerning the philosophy, principles, and indications of palliative care and, consequently, insecurity to deal with the prescribed conduct.[4]

It should be added that this unpreparedness of the palliative care professionals extends to the moment of the family's mourning, which can cause losses to the right to express their feelings, thoughts, preferences, pending issues at the time of death, and grief. The need to review the academic background of these professionals and encourage training and continuing education with a view to education for death should be emphasized, so that they can adequately deal with illness, death, and grief.[5]

Considering the aforesaid, the importance of knowing the experience of health professionals who assist patients in palliative care is emphasized, since this fact enables a deeper understanding of the assistance that these patients and their families receive.

This study aimed to analyze the discourse of health professionals about caring for patients in palliative care, at the time of the death and family's grief.

METHODS

It is a field research developed with a qualitative approach that was carried out in two hospitals in the city of *João Pessoa, Paraíba* State, Brazil. The sample, for convenience, consisted of ten health professionals (three nurses, three physicians, two psychologists, and two social workers) who assist patients in palliative care. The inclusion criteria were having, at least, one year of experience in assisting patients in palliative care, being interested and available to participate in the research and being active during the data collection period. Professionals who did not meet these criteria were excluded.

Data collection took place in the months of May and June 2019, through a semi-structured interview, using a script that covered data on the characterization of the participants and issues related to their experience in caring for patients in palliative care and family members, at the time of death and mourning.

For the analysis of the empirical material, the thematic content analysis proposed by Barding[6] was used in order to have access to the essence of the professionals' speeches about caring for patients and families in the context of palliative care, with the meanings grouped in two categories. To guarantee confidentiality and anonymity, the participants were represented by the acronym HP (Health Professional), followed by a numeral, considering the sequence of the interviews.

The research was approved by the Research Ethics Committee of the *Hospital Universitario Lauro Wanderley*, Health Sciences Center from the *Universidade Federal da Paraíba* (UFPB), under (*Certificado de Apresentação para Apreciação Ética* (CAAE) [Certificate of Presentation for Ethical Appreciation] No.11345919.9.0000.5188, respecting the ethical observances of scientific research, contemplated in the Resolution No. 466/2012 from the National Health Council.

RESULTS AND DISCUSSION

Two categories emerged from the analysis of the empirical material: Death in palliative care: understanding, feelings, and care; Grief in palliative care: assistance and difficulties.

CATEGORY I - DEATH IN PALLIATIVE CARE: understanding, feelings, and care

Health professionals express their understanding of death, report the most common feelings when caring for the patient at the time of death and describe some care for the patient. This is evident in the statements described below.

In the professionals' understanding, death is a natural, inevitable passage, the end of a cycle, a reflection of life experience, as shown in the statements:

> *Death itself I understand as an outcome of a cycle. It's part of life. It is the final process. Dying is like being born because being born is so natural, it is a cause for joy; death will have moments of sadness, family mourning, the patient's suffering, but we have to face it more naturally. (HP4)*

> *I think death is inevitable. It is a process that everyone will go through. (HP9)*

> *I think death is the beginning of a new life. It is something natural, something that we are afraid because of the unknown, but it is for the other side of the path, it is continuity. Death is the outcome and the outcome is opening. Well-worked death is life. It is transformative for those who care, for those who go and for those who stay. (HP5)*

> *Death is something that belongs to human beings, that belongs to life on Earth, it is a passage. It is the last big border that we have to pass. I understand that death will reflect what a person has done in life. (HP6)*

However, even admitting the idea of death as a passage and a continuity, other participants do not perceive it as a natural process, but as a loss and something difficult to accept:

> *I think the transition from life to death will never be natural. I see the afflictions! Death is a definite loss. I believe that some energy remains and that no one dies definitively. (HP7)*

> *My conscious side understands death as a passage [...] But it is not an easy thing to accept. (HP2)*

The professionals reported feelings of sadness, regret, fear, emotional shock, tranquility, as shown in the statements:

> *Sadness, because that treatment didn't work, for several reasons. (HP2)*

> *Dealing with these patients does not sadden me, it does not take away my calm, even though the other person expresses sorrow. That story: I'm centered, I don't feel sorry, it was good to have known, shared. It is as if I have an expression of regret from my own life. (HP7)*

> *It is the fear of suffering and I have no support. So, I'm going home with a very big emotional load! This has been going on for many years. (HP9)*

> *It is not a question of not being sensitive, but of knowing how to separate, of giving spiritual support, the hug, the handshake if necessary, without despairing about the situation. Nowadays, my understanding is more in-depth: at the exact moment, concerning the patient, I am calm. (HP10)*

> *I get emotionally shaken. When I see the patient dying and I see the companion, I cry with them. (HP1)*

Still, others claim that feelings depend on the bond they have established with the patient:

> *These feelings depend a lot on the bond, on my relationship with the patient. If it's one I've been monitoring, we'll end up getting involved. (HP8)*

> *We have greater contact with that patient and, inevitably, we have a greater attachment. It is impossible not to be touched by some stories. (HP4)*

> *When I see a patient who dies in a comfortable way because I took care, I feel good, comfortable, useful, I feel somewhat weighted. I feel sad when I cannot do what is scheduled when there is no time. There, it is a feeling of absurd helplessness. The understanding that it is not always the way we want it. This is important because it makes people more humble. (HP3)*

Professionals report palliative care offered to the patient at the time of death. Some emphasize the fulfillment of physical needs:

> *First, we focus, on the patient's need, if they are breathing:*

> *we try to put oxygen; if they are having an allergic reaction, try to take anti-allergic medication. But if none of this is going to solve it, then it is comforting. (HP1)*

> *We are always concerned with the comfort of that patient, with measures that will not prolong their suffering. (HP4)*

Other professionals report care, such as presence, being together, touching, holding the hand, radiating love to the patient, and releasing visits:

> *My presence. Right now, as much as it causes these afflictions, I want to think that in a way I calm some hearts (HP7)*

> *I remember some who, even sedated, I stayed together, took my hand, tried to speak so as not to be afraid, that the suffering was ending [...] and that he was not alone, I was there with him. (HP8)*

> *I once had a patient who was in a lot of pain. I knew he was going to die. So, what he wanted I did: I put him on his feet, I gave him the greatest comfort, because they were the last moments of his life. I love my profession, before my hand touches, the love I have radiates on the patient. When I see that the moment of death is approaching, I try to pass on to the patient that it is a moment of him and God. (HP3)*

> *Good communication. I think this is part of the care offered: offering your presence, donating [...]. Then comes the relief measures. A lot of people think: "Ah, pain control! So, it's morphine." Morphine comes later: the pharmacological comes long after the non-pharmacological. The palliative care professional needs to be a professional who integrates both the various dimensions of suffering and the dimensions of the profession. (HP6)*

> *I was concerned with allowing for more visits. I talked to the doctor who left it authorized, talked to the social service and released it during the shift (HP2).*

Others, however, claim that, at the moment of the patient's death, they move away, when the patient begins to show signs of imminent death, as a way of preserving themselves:

> *If it is a patient that I just visited and I started to realize that he is feeling sick, different color, more silent, I try to avoid it, I don't get too close. (HP9)*

> *Sometimes, I will not visit a patient in the ward or I will not visit the emergency room to preserve myself. (HP1)*

CATEGORY II - GRIEF IN PALLIATIVE CARE: assistance and difficulties

In this category, the professionals described the care they provide to grieving families and reported some difficulties they face at the mourning time. Assistance takes place while the patient's body is in the hospital and there is no systematic monitoring of grief.

> I *tell the family that his time has come, that the family has done its part. So, hug [...]. These are moments of visit and not of accompanying the mourning. (HP1)*

> *Family care takes place only while the body is in the hospital. After that moment, it turns off completely. There is no post-mourning follow-up. (HP10)*

> *In the immediate mourning, in the news of the death, but, after they leave here, the hospital does not do this service. (HP8)*

> *I cannot have satisfactory assistance that addresses the needs of that family at the time of death and grief if I have not had accompanied them before. (HP4)*

Some professionals report that they seek to talk to the family, understand the situation, give some psychological support, hug, and guide the families in the social aspect:

> I *try to assist in general, but understanding that for those who stay is also very difficult. (HP9)*

> *We don't know if we are doing it right, if we are doing it wrong. Sometimes you have nothing to say. Just hug. (HP2)*

> *Often, we are a psychologist, a social worker for families, we hold back crying, we try to be strong to give strength. (HP3)*

> *When the patient dies, I try to soften it up, I take this understanding to the family. (HP7)*

> *I think about grieving at the time of diagnosis. The main thing that I can give to the family at the time of mourning, before death, is time. I will allow them to work their grief with the presence of that person (patient). After death, it involves the act of being present and listening to what needs to be heard. The palliative care professional needs to understand that mourning is part of the process and must allow it. (HP6)*

The research participants showed some difficulties faced when assisting the family in the experience of mourning:

> *There is no such moment of mourning with the family. The hospital follows up until the moment of death. For post-mourning, we don't even have space. We as a professional feel very powerless. The number of professionals working is minimal. (HP9)*

> *And depending on the time, the "thing" gets more complicated, especially at night, weekends and holidays, because there are no psychologists, social workers to accompany family members. (HP10)*

> *We don't know what is right or wrong at that moment. And the bond that they (family members) create is sometimes not the same as mine. The health team, in general, should be better prepared to deal with these situations. It is even cruel to "put" these people to deal with it and learn in practice. And the professional who is dealing should be accompanied as well. (HP2)*

> *Some accept it when they spend a lot of time suffering. But, when it is a fulminating disease, fast, they do not accept it. Non-acceptance is the greatest difficulty. (HP3)*

> *The relationship with these terminally ill patients also has a counterpart for me. (HP7)*

> *There is a family that has the concept that good death is being in the Intensive Care Unit (ICU) and a family that accepts the proposal of a little more comfort. So, accept that the patient goes to the apartment, get out of the ICU, extubate, stop dialysis and everyone comes, prays, and everything. So, the main difficulties come from a family that doesn't have the same understanding of a good death as you do. Another difficulty is the professional's understanding of palliative care. (HP6)*

The reports of health professionals showed that most understand death as a natural process inherent to human beings. However, this perception is quite confusing. The experience of this same professional in accompanying the patient in the outcome of death becomes a distant observation or an experience brought from their personal life, far from being the experience alongside their patient.

The feelings of these professionals are suppressed, creating discomfort, and difficulties in the exercise of their profession. Feeling of helplessness, sadness, fear of clinging, and suffering create a "shield", where natural emotions are neither experienced nor shared.

Professionals, in general, are apathetic to these moments, as they do not allow themselves to form a bond. As a result, they lose valuable opportunities to hear the patient's life story through an assertive psychological listening that would enable a better application of drug therapies and the conduction of spirituality, covering the pillars of palliative care.

This conduct reveals an unconscious defense mechanism of denial, which protects professionals from suffering and pain. A study[7] points out that resistance to issues about death and the culture of denial surrounding it has a negative impact on health professionals, with the presence of defense mechanisms such as denial, resistance and depersonalization being common, contributing to emotional fragility and unpreparedness of these professionals. This can culminate in mental illness or exhaustion, and effective ways are needed to help them develop their grieving processes and claim improvements in individual and collective working conditions.

The finitude of the human being, in the context of palliative care, demands from health professionals an ability to deal with balance, in such a situation, with the care of the patient and family, in a comprehensive proposal. Given the complexity of the issues surrounding the process of death and dying, a study[2] highlights the need to talk about death and produce knowledge about it, to learn how to deal with death professionally, as dealing with birth, since it is professionals' responsibility to take care of both those who are about to be born and those who are about to die.

The academic background of health professionals needs to be reviewed, so that students and professionals can, through the educational process, exercise thinking, problematizing and modifying knowledge, feelings, values, and practices that, negatively, still represent death. In this way, skills and abilities will be developed that enable the planning of actions based on the care needs of each patient and family.[8]

Assistance to the patient and the mourning family occurs empirically. It is perceived in the reports of professionals that, when a bond is made with the patient or family members, this empirical assistance happens in a timely manner, that is, at the moment of the patient's death until the body leaves the hospital. The assistance of health professionals to families is made with a certain amount of insecurity and fear of making mistakes, generating anguish and, sometimes, a feeling of guilt, because they are not prepared.

Professionals still express the feeling of helplessness due to the lack of training, adequate physical space for this assistance and the shortage of professionals on weekends and holidays, which generates a huge gap in the process of assisting the mourning family.

Palliative care allows comprehensive assistance to the patient and family, from the diagnosis of a life-threatening disease to grief.[09,10] The promotion of a dignified death occurs when the health team has the capacity to welcome, support and assist the sick patient and family, through active listening and affection in the face of the situation. Therefore, professionals should be sensitive and clarify the doubts of patients and families, encouraging them to take positive attitudes in the process of death and grief.[09]

Palliative care should extend after the patient's death so that professionals offer support to the family in the grieving process.[11] As previously stated, grief is a natural reaction to the loss of a loved one. Therefore, the person who experiences it needs assistance so that they can return to life can healthily return to life and can understand death as something natural.[09] This is because, in the context of palliative care, "deaths" start to happen at the moment of diagnosis, when the patient receives the news that they have a serious, chronic illness. At that moment, something begins to die. Anticipatory grief begins: in the various phases experienced, it is present.

It is a phenomenon that is revealed in the own experience of those who find themselves in this situation and may present a lack of meaning in life, pain and an "ambiguity lived in the absence-presence" of the other.[12]

A study shows that, in anticipatory grief, regardless of the patient's illness, the family member has an emotional condition that requires professional intervention, to identify their needs that may present themselves in the physical, emotional, or social context.[13]

In palliative care, it is essential to bring professionals closer to the mourning family - which allows them to know their life history and offer them qualified listening. In this way, there will be conditions to plan and implement actions that make it possible to meet their needs and alleviate suffering: health education, coping strategies, interaction with spirituality, and religion. All of these are viable instruments and minimize suffering among family caregivers.[14]

There is an urgent need for a training and qualification policy for these professionals to be able to deal with the nuances of death and grief, in the sense of realizing what palliative care is for the family in question and adapting to the beliefs of that family, so that assistance in grief can be offered without violating these values, and the health team has an assertive and aligned understanding of what palliative care means and knows how to apply it.

CONCLUSIONS

The results of the study showed that health professionals do not have the necessary preparation to deal with the various situations that occur in the process of death and mourning, which causes losses in the care provided to patients and families.

Death and grief are structuring experiences for human beings. They need a good accompaniment to get through this phase without problems or summing up. The health team must be trained for such assistance from the moment of diagnosis, opening paths, building bridges so that the patient can reach this phase as lightly as possible, in the experience of a good death and - why not say? - in good mourning: dignified and healthy mourning.

This study was limited because it did not include other professionals in the sample, such as nutritionists, physiotherapists, and phonoaudiologists, which prevented an analysis of the experience of these professionals in caring for patients and families, in the process of death and grieving in palliative care.

It is hoped that this study can contribute to a greater knowledge about the experience of health professionals, in palliative care and the difficulties they face at the time of death and grief. It is suggested that further research can be developed in this area, in order to assess the experience of the palliative care team in caring for patients and families.

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