**NURSING PROFESSIONALS: UNDERSTANDING ABOUT PEDIATRIC PALLIATIVE CARE
PROFISSIONAIS DE ENFERMAGEM: COMPREENSÃO SOBRE CUIDADOS PALIATIVOS
PEDIÁTRICOS**

PROFESIONALES DE ENFERMERÍA: COMPRENSIÓN SOBRE LOS CUIDADOS PALIATIVOS PEDIÁTRICOS

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ABSTRACT

Objective: to investigate the understanding and practice of pediatric palliative care. **Method:** it is a qualitative, exploratory and descriptive study, in a Maternal-Infant School Hospital with 30 Nursing professionals. A sociodemographic questionnaire and semi-structured interview were used to collect data. The data was submitted to the Content Analysis technique. **Results:** professionals presented difficulties related to the understanding of the philosophy and objectives of palliative care and difficulties in working with pediatric patients under this care, highlighting the feelings of failure and sadness in dealing with the situation. As a coping strategy, the affective detachment of the patient and his family, the spirituality and the offer to the patient of a differentiated and humanized care are used as coping strategies. **Conclusion:** it is necessary to include palliative care in the academic training of professionals, favoring the knowledge of the subject and preparing the professional to deal with death and dying, as well as the need for a space in the health institutions that provide shelter for the difficulties of professionals working in this context. **Descriptors:** Palliative Care; Pediatrics; Pediatric Nursing; Death; Adaptation, Psychological; Humanization of Assistance.

RESUMO

Objetivo: investigar a compreensão e a prática dos profissionais de enfermagem sobre os cuidados paliativos pediátricos. **Método:** trata-se de estudo qualitativo, exploratório e descritivo, em um Hospital Escola Materno-Infantil com 30 profissionais de Enfermagem. Utilizaram-se, para a coleta de dados, questionário sociodemográfico e entrevista semiestruturada. Submeteram-se os dados à técnica de Análise de Conteúdo. **Resultados:** apresentaram-se, pelos profissionais, dificuldades relacionadas à compreensão da filosofia e aos objetivos dos cuidados paliativos e dificuldade em atuar com pacientes pediátricos que estão sob esse cuidado, destacando-se os sentimentos de fracasso e de tristeza ao lidarem com a situação. Empregam-se, com isso, como estratégias de enfrentamento, o distanciamento afetivo do paciente e de sua família, a espiritualidade e o oferecimento, ao paciente, de um atendimento diferenciado e humanizado. **Conclusão:** salienta-se a necessidade da inclusão de cuidados paliativos na formação acadêmica dos profissionais, favorecendo o conhecimento do tema e preparando o profissional para lidar com a morte e o morrer, assim como a necessidade de um espaço nas instituições de saúde que proporcione acolhimento frente às dificuldades dos profissionais que atuam nesse contexto. **Descritores:** Cuidados Paliativos; Pediatria; Enfermagem Pediátrica; Morte; Adaptação Psicológica; Humanização da Assistência.

RESUMEN

Objetivo: investigar la comprensión y la práctica de los profesionales de enfermería sobre los cuidados paliativos pediátricos. **Método:** se trata de un estudio cualitativo, exploratorio y descriptivo, en un Hospital Escuela Materno-Infantil con 30 profesionales de Enfermería. Se utilizaron, para la recolección de datos, cuestionario sociodemográfico y entrevista semiestruturada. Se sometieron los datos a la técnica de Análisis de Contenido. **Resultados:** se presentaron, por los profesionales, dificultades relacionadas a la comprensión de la filosofía y a los objetivos de los cuidados paliativos y dificultad en actuar con pacientes pediátricos que están bajo ese cuidado, destacándose los sentimientos de fracaso y de tristeza al lidiar con la situación. Se emplean, con ello, como estrategias de enfrentamiento, el distanciamiento afectivo del paciente y de su familia, la espiritualidad y el ofrecimiento, al paciente, de una atención diferenciada y humanizada. **Conclusión:** se destaca la necesidad de la inclusión de cuidados paliativos en la formación académica de los profesionales, favoreciendo el conocimiento del tema y preparando al profesional para lidiar con la muerte y el morir, así como la necesidad de un espacio en las instituciones de salud que proporcione acogida frente a las dificultades de los profesionales que actúan en ese contexto. **Descritores:** Cuidados paliativos; Pediatria; Enfermería Pediátrica; Muerte; Adaptación Psicológica; Humanización de la Atención.

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INTRODUCTION

The palliative term of "palium" was originated, which means mantle, cover, protect, ie, pallia is to reduce pain and suffering, from the moment of diagnosis and especially when patients can no longer be supported by curative medicine.¹

Palliative Care is defined as:

An approach that promotes the quality of life of patients and their families in face of diseases that threaten the continuity of life, through prevention and relief of suffering. It requires the early identification, evaluation and impeccable treatment of pain and other problems of a physical, psychosocial and spiritual nature.^{2:5}

Quality of life in palliative care is understood as comfort, relief and symptom control, spiritual and psychosocial support. For this purpose, a multidisciplinary team (physicians, nurses, psychologists, psychiatrists, physiotherapists, social workers and spiritual support) is required, with a humanized vision focused on valuing life and promoting integral care.³

The principles are: to promote the relief of pain and unpleasant symptoms; affirm life and consider death a natural process; not accelerate, or postpone death; integrating the psychological and spiritual aspects of patient care; offer a support system that allows the patient to live as actively as possible until the moment of his death; offer a support system to assist the family during the patient's illness and in coping with mourning; to foster the multiprofessional approach to focus on the needs of patients and their families, including follow-up in mourning; improve the quality of life and positively influence the course of the disease; initiate care as early as possible along with other measures of prolonged life and include all the investigations necessary to better understand and control stressful clinical situations.⁴

In accordance with Law 52/2012 on the Basis of Palliative Care, this type of care should be exercised by trained and trained professionals, aiming to promote well-being and quality of life for patients with severe or incurable diseases who are experiencing intense suffering. It is also necessary to respect the autonomy, individuality, dignity and desires of the patient.⁵ The following care modalities stand out: hospital admission; outpatient care; home care; the emergency room service, hospice and day hospital.⁶

The first Palliative Care Service was created in 1983 in Rio Grande do Sul, but the Brazilian Association of Palliative Care (BAPC) was founded in São Paulo in 1997 alone. It is added that, currently, it is possible to notice an expressive growth of this modality of care in Brazil, however, there is still no national policy focused on it, because, for that, paradigm changes related to the health-disease process and an effective articulation between the health network.⁷⁻⁸

This is a recent area of medical practice that, despite many achievements in recent years, remains unknown and suffering prejudices by the health team itself, hospital managers and Judiciary.⁹

Specifically, in Pediatrics, palliative care is explained as:

Active and total care provided to the child in the context of his / her body, mind and spirit, as well as the support offered to his / her entire family, from the beginning of the diagnosis of the disease, alleviating physical, psychological, social and spiritual suffering, as well as offering family support.^{2:6}

Pediatric Palliative Care presents some particularities, such as: fewer patients under this care; possibility of survival until adulthood; parents and family members who experience loss and grieving in advance; the family becomes involved with the care of the patient, and healthy siblings are excluded from this process, which can lead to an emotional vulnerability; difficulties in expressing the feelings of the child and relatives; difficulties in the family's willingness to care for themselves and to remain in the hospital for a long period of time; diseases that occur in the stage of physical, emotional and cognitive development, being essential to guarantee the continuity of the educational process.¹⁰

It is revealed that, like the entire multidisciplinary team, Nursing professionals play an extremely important role in Palliative Care, since they provide the necessary care and meet the needs of patients on a daily basis. It is necessary that these remain calm and emotionally balanced, to face the tensions that involve the process of death and dying, recognizing that there is always something to do for patients, even in the process of finitude.¹¹

OBJECTIVE

- To investigate the understanding and practice of Pediatric Palliative Nursing Care.

METHOD

This is a qualitative, cross-sectional, exploratory and descriptive study carried out in a Pediatric Intensive Care Unit (ICU), a Pediatric Oncology Outpatient Clinic and a Pediatric Infirmary at a Maternal and Child Health Hospital located in the interior of the State of São Paulo, in the period from August 2016 to October 2017.

The sample was selected in random order, by means of a lottery of the professionals who work in the units chosen for being or have already provided palliative care to children or adolescents. As inclusion criteria, professionals with more than three months of service were adopted and, as exclusion criteria, professionals with cognitive deficits or who had some mental disorder that made it impossible to answer the questionnaires.

A sociodemographic questionnaire containing data on the identification, training time and performance in the area and the work unit and semi-structured interview were used as data collection

materials, both elaborated by the researcher according to the objective of the study. Five questions related to understanding the philosophy and principles of palliative care, experiences with care modality, academic training, experiences related to the death and dying process, and personal coping strategies for this process are included in the interview.

Subsequently, the data obtained were transcribed and transcribed and submitted to Content Analysis,¹² which describes and interprets content by conducting qualitative and quantitative descriptions, interpreting and reaching an understanding as a whole. to the Ethics and Research Committee under the number CAAE: 57308216.5.0000.5415, approving it under Opinion No. 1,690,661. Data collection was started after study approval and all participants signed the Free and Informed Consent Term (FICT)).

RESULTS

A total of 30 interviews were carried out and the sociodemographic data of this population.

	aGE	Sex	Martital status	Children	Religion	Unit	Training	Time training
P1	25	F	Single	No	Evangelical	Oncology	Nurse	5 years
P2	38	F	Married	Yes	Catholic	Oncology	Nurse	5 years
P3	22	F	Single	No	Evangelical	Infirmary	Nurs. Tec	2 years
P4	25	F	Married	Yes	Catholic	Infirmary	Nurs. Tec	3 years
P5	24	F	Single	Yes	Evangelical	Infirmary	Nurs. Tec	5 years
P6	34	F	Married	Yes	Evangelical	Infirmary	Nurs. Tec	3 years
P7	31	F	Married	Yes	Evangelical	Infirmary	Nurs. Tec	2 years
P8	39	F	Married	Yes	Catholic	Infirmary	Nurs. Tec	14 years
P9	35	F	Married	Yes	Catholic	Infirmary	Nurse	12 years
P10	29	F	Married	No	Catholic	Infirmary	Nurse	8 years
P11	22	F	Married	Yes	Evangelical	Ped ICU	Nurs. Tec	1 year
P12	27	F	Single	No	Catholic	Ped ICU	Nurs. Tec	8 years
P13	26	F	Single	No	Catholic	Ped ICU	Nurs. Tec	6 years
P14	45	F	Married	Yes	Catholic	Infirmary	Nurse	24 years
P15	47	F	Divorced	Yes	Evangelical	Infirmary	Nurs. Tec	22 years
P16	25	F	Married	No	Evangelical	Infirmary	Nurs. Tec	3 years
P17	26	M	Single	No	Evangelical	Infirmary	Nurs. Tec	5 years
P18	36	F	Married	Yes	Catholic	Ped ICU	Nurs. Tec	12 years
P19	32	F	Single	Yes	None	Ped ICU	Nurs. Tec	8 years
P20	30	F	Married	Yes	Catholic	Ped ICU	Nurs. Tec	10 years
P21	35	F	Married	Yes	Catholic	Ped ICU	Nurse	2 years
P22	34	F	Married	Yes	Catholic	Ped ICU	Nurse	8 years
P23	26	F	Married	No	Spiritist	Ped ICU	Nurse	5 years
P24	20	F	Single	No	None	Infirmary	Nurs. Tec	3 years
P25	21	F	Single	No	Catholic	Infirmary	Nurs. Tec	2 years
P26	29	F	Single	No	Catholic	Oncology	Nurse	7 years
P27	52	F	Divorced	Yes	Catholic	Ped ICU	Nurs. Tec	18 years
P28	39	F	Married	Yes	Evangelical	Ped ICU	Nurs. Tec	17 years
P29	26	F	Married	Yes	Not stated	Ped ICU	Nurs. Tec	6 years
P30	25	F	Single	No	Catholic	Ped ICU	Nurs. Tec	6 years

Figure 1. Socio-demographic data. Key: Nurse: Nurse (o). Nurs. Tec: Nursing Technician. F: Female. M: Male. Ped ICU: Pediatric Intensive Care Unit. São Paulo (SP), Brazil, 2016-2017.

The participants were distributed among nine nurses and 21 nursing technicians, with a mean age of 30.8 years and an average of seven years of professional training; only one participant is male, just over half the

professionals have at least one child and are married. He referred, with regard to religiosity, to only two participants, to have no religion and one did not answer this question.

At the end of the transcript of the interviews, five categories of responses were divided between: Understanding of Palliative Care; Experiences and feelings about care; Academic training; Emotional preparation facing the process of death and dying and coping strategies. The following categories are detailed.

DISCUSSION

♦ Understanding Palliative Care

In the majority of responses, it is perceived, in relation to the understanding attributed to palliative care, that it is mainly seen as comfort and welcome offered to children and their families, using medicines for pain relief and promotion of quality of life. Patients are understood by these professionals as individuals with no prognosis of cure, thus highlighting that this care is linked to a vision of terminality.

Therefore, palliative care is, in my view, the care we give to a patient when he has no chance of a cure, to provide a well-being for him [...]. It will only provide pain relief [...] so he can survive with this diagnosis in a more comfortable way, to bring better performance to him during life yet, for as long as he will survive with that diagnosis. (P26)

[...]that does not have a good prognosis, that the disease, the clinical picture does not have a prognosis, a good evolution and ends up progressing to Palliative Care, which is a care, thus, more to ease the pain, the suffering of the child, is the same hygiene care, everything, both physical and psychological care, but, without thinking about healing, it is more for quality of life [...]. (P9)

It is noteworthy that the literature is in line with the statements presented, demonstrating that the objectives of Palliative Care are linked to quality of life, well-being and humanization, providing active, rigorous and specialized care to patients suffering from serious diseases, incurable, advanced and progressive.¹³⁻⁴

It was stated in some interviews by the participants that care in Palliative Care is not only focused on the care of the body, highlighting the importance of the psychosocial aspects of the patients and their relatives. The interviewees are referred to the emotional pain, the anguish and, even, the psychological malaise experienced by the patient.

[...]you have to take care of the patient, not only the patient's pain, but take care of the patient, the family, not only take care of physical pain, but emotional pain

[...] it has to ease his suffering, either with a conversation [...] to give a hug, to give even a bath in the bed with warm water the way he likes [...]. (P1)

[...]for me, it would be more when the child no longer has a prognosis of the disease, there you will take care of more of relieving symptoms, the emotional part and even physical pain. (P30)

The responses are in line with a survey that presents, in its results, responses from nurses, nursing technicians, physicians and other professionals, who affirmed, as essential in Palliative Care, the biopsychosocial attention, besides the physical symptoms and the relief of the pain.¹⁵

It should be noted that 14 (46.7%) interviewed do not fully understand the objectives and philosophy of Palliative Care, according to the proposed definition.² It is noticed that this theme is still marginalized from the daily life of some professionals.

You take care of someone who no longer has expectations in the eyes of doctors, no longer has life expectancy ... I think that's it. (P24)

Oh, for me, the child is already, has no way of, has invested everything that had to invest, will only minimize her suffering to have a quieter death, right?! (P4)

It is observed that Palliative Care began in Brazil only in the 80's, causing delay or even the inexistence of this issue in the curricular curricula of health care courses, which may justify the lack of knowledge presented in the speeches of the participants.¹⁶

On the other hand, similar research was carried out with 159 Nursing professionals in a Spanish hospital of third level, pointing out, as a result, that the participants show a sufficient knowledge about the Palliative Care, a fact that can be justified by Spain include in the graduation, Palliative Care with a heterogeneous study plan on the subject, in addition to a postgraduate program.¹⁷

It is understood, for many health professionals, the impossibility of cure as a justification for the execution of limited care, which confronts the principles of Palliative Care in which professionals must offer a support system that enables the patient to live as actively as possible, until the moment of his death, offering a support system to assist the family members.¹⁸

♦ Experiences and feelings about care

It is emphasized that, in Palliative Care, the Nursing team, as well as other

professionals, should promote integral care to the patient involving biopsychosocial and spiritual aspects. It is necessary for the professionals involved in this practice to be provided with sympathy, love, compassion, affection and dedication, since the comfort and well-being of the patient should be prioritized.¹⁹

It is pointed out that, by actively participating in the care process, Nursing professionals experience situations of suffering, anguish, fear, pain and revolt in their daily lives, often experiencing or expressing feelings and reactions similar to those of their patients, interfering directly in their personal lives.²⁰

It is an experience that moves us a lot because we end up feeling the pain of the family, end up getting involved, even unintentionally [...] my feeling about it is pity, of not being able to do anything, it is a feeling of do. (P15)

[...]we try not to get caught up, but it's complicated, but we try to separate things a little, which is work, which is outside, but it is difficult. (P17)

"At the beginning of my profession, I would go out crying almost every day of the room because, this way, the family is already prepared, but the people, who are entering for the first time, are not to see that scene. (P19)

This bond is increased when the patients are children, making the lived experiences meaningful and affectionate both for the professionals, as for the children and relatives.¹⁰

[...]it is difficult, even more so, with a child [...] the mother was with her on her lap and said: Let my daughter rest, for God's sake. And in that, the head nurse came and I'm very emotional, so, at the time, my eye was already filled with water and the nurse told me to leave the room, then I left and it happened: she passed away and we prepared the body and everything. So, it's hard for this part [...] you can not do anything because, whether you want to or not, you can not do it, then you feel a little helpless, so helpless [...]. (P25)

When asked about their feelings and feelings about Palliative Care, it is identified that the greatest of professionals shows frustration and impotence in the face of limitations and losses.

[...]it is very difficult to see the suffering, right, and we feel powerless to not do it, so we do the most we can, but we know that, because of the course of the disease, there is not much more to do. And it is difficult to see the child, the mother to suffer, it is difficult, it is not easy. (P9)

"It is a feeling, sometimes, of incapacity because there you already know, so you try to give the best, but you also can not [...]. (P30)

It was pointed out, however, by some professionals, that these experiences are considered positive for personal life.

[...]I took everything into my personal life [...] to give more value in life, I have two small children, so we end up, so it is changing the concepts out of here. So I think the experience was, in terms [...] positive, because I took it out and, in terms of the child, there is no way, only if you are a robot, but we end up getting attached, creating a love for that child and, of course, never forget, I never forget, ever, of all the children that we took care of in Palliative Care, I remember all. (P6)

[...]it was a good experience because, on the other hand, we learn to value others' feelings, you learn not to be so selfish, I have learned this, you learn to collect the suffering of the other person, to be supportive, you learn to to be more human seeing a child like that; I, when I started working with children, I started to be more human, you know?! [...]. (P12)

It is inferred that the statements presented are in agreement with the research²⁰, which demonstrates, in its results, Nursing professionals anguished and emotionally fragile in the face of impotence and unpreparedness for the work in Palliative Care and the termination process. It was verified, in another research,²¹ that the professionals at the beginning of the trajectory, in this mode of care, reported frustration and impotence.

They become emotional stressors, such as anguish, exposure to suffering, difficulties in answering difficult questions to patients and relatives, repeated deaths, and even personal discomfort in the face of suffering and death, part of daily life of those who work in Palliative Care. Thus, it is necessary to provide professionals with strategies that can alleviate emotional overload, increase job satisfaction, and improve patient care.²²

[...]we do not have any psychological support for this at the hospital and we feel helpless because the family is there ... we have to know how to deal with the family [...] with the patient too [...]. (P14)

[...]I could not even work the other day. I was terrible and I think here, in the hospital, I even had to have a psychologist to work with us, with the staff, because it was horrible my experience with Palliative Care [...]. (P24)

It is noteworthy, from the speeches expressed in the interviews, the need to offer emotional support to the professionals due to the attrition caused by the difficulty in dealing with children in terminality, mourning and inassertiveness.²³

Academic training

In relation to the academic preparation specifically addressed to Palliative Care, the theoretical and practical insufficiency, being the answers obtained from the questioning: "In your opinion, your academic training prepared you to deal with patients in Palliative Care?"

No, it did not. Neither the question of formation, nor in relation to the psychological, was not prepared. (P29)

No [...] in my academic training, I had never really heard about Palliative Care [...] the basis I have is very little [...] I was learning throughout the profession [...]" (P26)

No, nor was this word called Palliative Care. (P22)

No, in college, I did not see anything about it. (P18)

It is demonstrated that when asked if they were prepared to deal with this public, the majority was negative, and only three participants said they had been prepared for work in Palliative Care.

Yes, in school, they had enough, they talked about it, in the Psychology part, they also talked, prepared a lot. Everything they had said happened. (P4)

Yes, from the time of school, during the course, we are prepared, yes, the teachers explain to us, teach us to, when we arrive and come across the situation, we are already prepared. (P16)

Yes, in college, we experienced it a little; in my college, we did some work at home, so I had a little contact yes, especially with the elderly, I already had more or less a notion. (P20)

It is corroborated, by the results, the literature,⁷ when it is pointed out the need to reformulate the curricular curricula of the health courses so that Palliative Care can be included and the need to broaden the discussion on the subject.

In a study carried out with 37 professionals (physicians, nurses, nursing technicians and physiotherapists) in an Intensive Care Unit, the objective was to know their perception about Palliative Care, that the participants were not prepared to deal with the patient under this care for lack of knowledge, adequate training and involvement of all members of the multiprofessional team.²⁴

♦ Emotional preparation facing the process of death and dying

It is thought that Palliative Care will not bring healing to the patient, but may provide a better quality of life and, possibly, a worthy death. It becomes such an increasingly necessary practice because, even without the possibility of cure, patients continue to need care to alleviate their suffering and that of their family. Comfort should be provided by the professionals, making the life that remains to the patient as bearable and meaningful as possible without accelerating death.⁶

The health professionals are prepared, in this study, the Nursing in their professionalization, to cure the patients at any cost and, when this is not possible, they may wish isolation because they do not have the adequate support to your care. The importance of the introduction in Palliative Care since the formation is emphasized, so that the professionals can understand and accept the finitude of the human being.²²

It was affirmed, by professionals, when asked about their experiences in the process of death and dying of children or adolescents, in the following lines.

Painful, extremely painful, very painful, has nothing to say about it, I put myself in the place of the father and the mother, there is nothing to talk about before it, it is very painful. We are overcoming with time, but we have nothing to talk about. (P13)

[...]my, I'm sad, I cry, I cry, I cry, I go out there, I do my things, I fix it, but, after I leave, I go to the bathroom and cry a lot for it, it's like I'm relieved, you know ?! That feeling, like that, is not a feeling of guilt, but of uselessness, I keep thinking, "Wow, I've done so much and it seems I did not do anything" [...] I cry a lot and relieves, I comfort myself crying because I know it will ease the pain I'm feeling now, I'm like this and no use, it's been seven years and I always cry. (P12)

The difficulty of health professionals in dealing with death in the current literature is highlighted, highlighting that it is associated to the traditional teaching method, centered on the cure and rehabilitation of the disease, in this way, often decontextualized from reality.¹⁶ It is added that both the family members and the multiprofessional team suffer with the death of the child and, thus, seek to find mechanisms to face loss and mourning.²⁵

It is warned that in Palliative Care, understanding about the various forms of spirituality can be a positive strategy for

dealing better with the death process. Spirituality can be an ally both for the patient and for the professional who is also in suffering experiencing this process with the relatives.³

The spirituality during the interviews was emphasized by three participants as one of the tools to deal with the death process, as revealed in the following testimonies.

I believe that everything has its time, everything has the right time to happen, God gives you, God takes you when He thinks you should. So, children are angels and they have right place on Daddy's side of heaven, so if God wanted to, we just have to accept it, is it going to be a pain? Go, it will be a pain! We always have to ask God to heal, to take care of us, wherever this child is, to take care of people because they are angels and that's it. (P1)

Yeah, experiencing is kind of complicated, right ?! [...] And we have to look, I think that in God, in every religion, I do not know, to fortify our mentality, which is our head, which is our psychological and our heart, because if this comforts the family, the child, we also have to comfort ourselves. (P2)

I have a different thinking about death, maybe because of religion, of course if it is with us it is different, but I live this process, so, we have fulfilled our time, that everyone has a time before of what God has planned for each one of us, and I believe that if that time comes, we have to accept the will of God; a lot of pain, a lot of suffering that I know is not easy, but, somehow, we need to cling to some religion, something that will make us the best, that will make us accept and try to have comfort over death. (P15)

It is emphasized, among the attributions of the professionals, that their actions and interactions occur with the patient and his relatives from his arrival at the hospital, until his departure, whether by discharge or death. This affective bond was highlighted among the interviewees, being pointed out as a factor that makes it even more difficult to elaborate the process of death of the child or adolescent.²²

[...]is very difficult, you have to have a psychological, we try, the most, to be the professional, to a certain extent, but there is no way, we are human beings, [...] wanting or not, how we get very time with the child and the person stays here for a long time, the person gets very attached to us [...] has to have a very large psychological and so, sometimes we can sometimes not, or when it passes or When we go home, we'll fall down at home

so we do not have to be passing in front of the mother, right? (P6)

[...]is very distressing, I try very hard to give comfort to the family, if she gives me an opening, to talk with them, only that, this way, is very distressing for the staff and for the family because, as such, they usually have a long contact, is not a child who arrived here today and died in the afternoon, did you understand? It's a long contact. You talk like this: "you have to be professional", that's fine, you're professional, you try to be professional, but, guys, you do not. You live months, you talk months [...]. (P8)

[...]it is difficult to deal with death, sometimes we spend so much time with that patient that we take a lot of love, but enter into that issue of separating what is work, because when the child suffers we end up suffering together, but we need to be strong to comfort the family too. It's a bit difficult, but in everyday life we're learning to deal. (P16)

It is necessary, in order for the patient to receive the support to live as actively as possible and obtain a dignified death, that the team shows affection, respect and readiness to be on their side in the imminence of death. It is reported in the literature that, despite the relevance of this issue, many professionals avoid verbal contact with terminal patients because they can not deal with feelings related to the situation of finitude.²⁶

[...]Oh, my God, it sucks, we never want it here, we always want it, it's horrible, ours, it sucks, imagine the mother, right [...] if I could not be here right now, I would not be. (P3)

It is evident, for the majority of professionals, that death is still considered a taboo, so dealing with it is a daily challenge. It is often related to the death of patients to professional failure and is not associated with an inherent circumstance in life. It is noticed that for the Nursing team, it is not easy to deal with death, and this causes some of these professionals to try to escape the situation or the care of these patients.²⁷

◆ Coping Strategies

It is warned that health professionals working in Palliative Care may be vulnerable to occupational stress due to the complexity of situations experienced daily such as: death, the process of finitude and family distress. In this way, the professionals are looking for coping strategies to face or escape from threatening or stressful situations.²⁸

Coping can be defined as behavioral changes to drive specific demands that can

be seen as overhead; Thus, they act as a set of behavioral responses, in the face of a situation, a generator of stress in an attempt to adapt.²⁹

In response to the question "What personal strategies do you use to deal with this process?".

Look, I do not think [...] I need to hang up, I can not take things from here to there, so I do not think, I turn it off, I do not comment, these things and I'm quite Catholic, so I believe this part help. (P20)

Oh, it's complicated, we get involved enough, both with the child, with the family, with the mother, everything, but we try to take turns, not always stay with the same child, change the employee because otherwise, becoming a little more complicated, clinging too much. (P17)

The strategies of coping are characterized in two categories: (1) problem-focused coping strategies in which the professional is committed to modifying the stress-generating situation, such as training achievements and meetings with the team to expose difficulties in Group; (2) coping strategies focused on emotion, in which the professional seeks to regulate his emotional state in the face of the stress experienced, such as religion, being a way to understand and ease suffering, distractions outside the work environment and the support of family members and friends.²⁹

It is noticeable in the interviews, predominantly, that the participants use coping strategies focused on emotion, as pointed out in the highlighted speeches.

I prefer not to take to my house, like this, and I prefer ... I have a friend here at the service, I prefer, the two of us, we leave here and we both go, we go out together and comment among us [...] people go out, get distracted, go to the movies, understood ?! We both commented between us and ran out. Now, like this, I do not like to take it home because you end up taking it to life, right?!. (P24)

Today, I try to get out of here and know that I have done my best, a good job and try to forget, trying to forget, thus, to get home and disconnect from my work, to live my family, my day to day, my leisure, to be able to handle it better [...]. (P18)

It is understood, in light of the above, that Nursing professionals tend to separate their personal life from the feelings lived in the professional context, thus seeking their friends and family to share emotions and anguishes, as well as practices of leisure activities.¹⁵

It should be noted that most interviewees point to spirituality as the main coping strategy.

[...]I believe in the afterlife and that nothing is by chance and, if it happened, there is a reason to happen; most of the time, I try not to get emotionally involved, psychologically, with the child and the family, but, from time to time, it happens, then we suffer too, but we try to conform. (P23)

[...]Before you come, you have to pray, prepare yourself, I believe that. Taking God, I think it works better, so to work in the hospital [...] it's not easy at the hospital [...] we put ourselves in the mother's place to know what pain she's going through. It is this. (P5)

[...]I think God is the only comfort. I think it's the only strategy because if you stop to think a lot, we leave here half-freaked, I think that's it. (P29)

In the face of traumatic and stressful situations, especially in the health-disease process, the spiritual dimension has been revealed as an important internal resource that helps professionals to cope with adversity. Spirituality is understood as a form of resilience to face the difficulties of psychic and physical order and to help the nurse to assume a posture of acceptance before death.³

They predominantly presented themselves, as far as religion was concerned, as Christians (evangelicals, spiritists or Catholics), and only two professionals claimed to have no religion, and another did not respond to this question.

Another strategy was found in the interviews, the "establishment of barriers", where professionals affirm that they seek affective distancing in their relationship with patients and relatives.

[...]I try not to get too involved, I give my best to the patient, I love everything, but I try not to get too involved because I know that if the child leaves, then I will suffer along with the family too; there, I already have my problems, my life, there I will not be able to carry that too, if death happens. (P16)

I try not to take this home, or my people, but us, right ?! [...] We create a blockade, right?!; we have to create a blockage between that and our private life, but it is difficult, very difficult. (P3)

This distance and indifference are considered as a positive coping strategy adopted by nursing professionals in the face of finitude, because it is through fear of death that nurses end up moving away from

the terminally ill and unconsciously focus their attention on work and in the process of illness with the aim of removing expressions of fear and death.¹⁵

Finally, it is considered that the coping strategy used by professionals depends on the situational factors, that is, professionals can use or change strategies depending on the moment they are experiencing and the stressful situation.²⁹

CONCLUSION

It was possible to identify, from the results, that 14 participants did not understand the philosophy and objectives of Palliative Care, and the others understood totally or partially, referring mainly to quality of life, comfort and relief of the physical and psychic suffering of the patient.

It was evidenced, however, that the academic preparation was insufficient for the practical action, highlighting the need for training related to the thematic aiming for a quality and humanized service.

Emotional issues, professionals, feelings of impotence and frustration about the termination process, emotional fragility in dealing with these patients and showing the need for emotional support are revealed.

It is suggested, from the above, the training of professionals on the subject and the offer, to them, a space for the exhibition and the elaboration of their emotions.

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