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RESEARCH ARTICLE

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NURSING ASSISTANCE TO THE FAMILIES OF CHILDREN WITH CANCER IN PALLIATIVE CARE IN THE TERMINAL PHASE OF LIFE

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ABSTRACT

Objective: to analyze the nurses' performance in assisting the families of children with cancer in Palliative Care who are terminally ill in the light of the Peaceful End-of-Life Theory. Materials and Methods: qualitative research, carried out with 15 nurses. Data collection took place from October to December 2019, using the interview technique, based on a script containing questions related to the objective proposed for the study and guided by the concepts of that theory. The data obtained were submitted to content analysis. Results: two categories were developed from the analysis which was based on the Peaceful End-of-Life Theory: nursing assistance to the families of children with cancer in Palliative Care, with emphasis on providing comfort in the face of anticipatory bereavement; orientation to the families, valuing their presence and inclusion in the assistance of children with cancer in Palliative Care to promote a peaceful end to life. Conclusion: the study has demonstrated that the nurses' performance in assisting the families of children with cancer in Palliative Care who are terminally ill, when supported by the theory based on the Peaceful End-of-Life Theory, improves the quality of care provided at the end of life to both the children and their families.

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INTRODUCTION

Nursing is a profession that has as its scope the care of the human being throughout the vital cycle. The nurse, as a healthcare team professional, acts in different assistance scenarios, such as Basic Health Units, outpatient clinics, and hospitals that treat patients with different pathologies and age groups, such as the pediatric oncology field. In this field, the care of children with cancer is very complex, since it is a life-threatening disease, and therefore it is essential to recommend Palliative Care to assist children with this diagnosis and their families.^{1,2} In the pediatric field, Palliative Care aims to improve the quality of life of children suffering from incurable diseases, by promoting an integral and humanized assistance provided by a multi-professional team, which encompasses the care of their biopsychosocial and spiritual needs, starting with the diagnosis of the pathology up to the final stage of life, including support to their families throughout the entire disease process until bereavement.^{3,4} The work of a multi-professional team is of great relevance in assisting children with cancer in Palliative Care, in the hospital setting,⁵ the nurse being the professional who stands out the most, whose job is to stay most of the time with the patients, assisting them throughout the entirety of their hospitalization, as well as providing

support to their families from the admission of their loved ones to the phases of terminality and bereavement.⁶ Studies highlight the importance of including the families of children with cancer in Palliative Care throughout the care process provided by nursing professionals, especially when they reach the final stage of life.^{7,8,9} Therefore, it is up to the nurses to contemplate the families in assisting the children with cancer in Palliative Care in the end-of-life phase. Thus, nursing professionals must seek to support their clinical practice in a nursing theory, such as the Peaceful End-of-Life Theory (EOL Theory). This theory was proposed by nurses Ruland and Moore, from the experience of caring for terminal patients under Palliative and Family Care. For the theorists, peaceful death occurs when there is peace of mind, the absence of signs and symptoms of the patient's suffering, and when the family accepts death or its imminence.¹⁰ Considering the EOL Theory's relevance in guiding the clinical practice of nurses in assisting children with cancer in Palliative Care in the end-of-life phase and their families, and bearing in mind the reduced quantity of publications about this theory's applicability in pediatric oncology in the national and international scenario, as evidenced in a survey carried out previously, this study aimed to analyze the nurses' performance in assisting the families of children with cancer in Palliative Care in the end-of-life phase, in the light of the Peaceful End-of-Life Theory.

MATERIALS AND METHODS

Type of study: This is a field research of qualitative nature guided by the Peaceful End-of-Life Theory. To ensure the stringency of the proposed research, the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines checklist was used. This instrument consists of 32 items, which guide qualitative studies and assist researchers in the study development. This instrument contributes to improving the quality of qualitative studies.¹¹

Research site: The study was carried out in the pediatric oncology sector of a leading philanthropic hospital for the treatment of cancer in children, located in the city of João Pessoa, capital of Paraíba - Brazil.

Study participants: The study population was composed of assistential nurses who work in the pediatric oncology sector of the hospital selected for the study. To select the sample, the following inclusion criteria were considered: the professionals should have at least one year of experience of care activity directed to children under Palliative Care and be active during the data collection period. Professionals who were absent from the care activity due to leave, vacation, or other reasons were excluded from the sample. Therefore, the sample consisted of 15 nurses.

Data collection instruments and techniques: The interview technique was used to enable data collection, which was based on a script containing questions related to the objective proposed for the study and guided by the concepts of the Peaceful End-of-Life Theory. This stage was carried out from October to December 2019, through weekly meetings and weekend meetings in the morning, afternoon, and evening shifts. The research protocol was approved by the Research Ethics Committee (REC) of the Health Science Center (HSC) of the Federal University of Paraíba (FUPB), under legal opinion number 3.303.655.

Data analysis: The empirical data obtained were qualitatively analyzed using the content analysis technique proposed by Bardin.¹² This technique includes the following phases: pre-analysis; data exploration; and data treatment, inference, and interpretation.

RESULTS

The study sample consisted of 15 nurses working at the hospital selected for the proposed research. As for the participants' profile, the sample was predominantly female, with 12 professionals being female out of the 15 participants. Their ages ranged from 33 to 55 years. Regarding their time in service, it varied from 2 to 36 years; while their time working in pediatric oncology varied from 2 to 13 years. Concerning their qualification, all of them are specialists, with 11 participants working in nursing fields and 4 participants being Palliative Care specialists. Based on the qualitative analysis of empirical data from the testimonies of the nurses participating in the study, in the light of the Peaceful End-of-Life Theory, two categories emerged, presented below:

Category 1 - Nursing assistance to the families of children with cancer in Palliative Care, with emphasis on providing comfort in the face of anticipatory bereavement

In this category, the nurses emphasize the importance of valuing comfort as a form of support for family members in the face of the imminent loss of the child, during the anticipatory bereavement phase, as the following reports highlight.

During my time assisting the families of children with cancer in Palliative Care in the end-of-life phase, I have tried my best to provide support and comfort to them, since I am a mother and I imagine how painful it must be to experience the anticipatory

bereavement of a child and to know that at any moment the child could leave us. [...]. (NURSE 1)

It is very difficult for the families, especially for the children's parents, to know that their children are suffering from a serious illness and will have only a few days left to live [...]. They begin to experience anticipatory bereavement before the possibility of their children's premature death. I try to provide support to everyone in the families to comfort them in this very difficult moment in their lives. (NURSE 3)

I try to offer support and comfort to parents especially during the anticipatory bereavement phase [...] since I am a mother and I know how painful the moment of a child's departure must be, especially when the child is still an infant. (NURSE 4)

I try to offer support to comfort them during the process of anticipatory bereavement and also to ease the visit of relatives and people dear to the children [...]. (NURSE 6)

I try to provide all the support I can to the family members and comfort them to minimize their suffering a little in face of the final stage of life of a child with cancer in Palliative Care [...]. The anticipatory bereavement becomes very painful for every family when they realize that their loved one is in the terminality, especially when their loved one is a child. (NURSE 7)

It is very sad to witness the families' suffering, especially when they know that their children will depart at any moment. [...]. I always try to be closer to the families when their children are in the final stage of life to offer them support and comfort in the face of anticipatory bereavement [...]. (NURSE 10)

It was very difficult at first to deal with children with cancer. Their families and the whole team go through a lot of suffering. The most painful phase is when the children reach the final stage of life [...]. In this anticipatory bereavement phase, I try to comfort the families during this difficult and painful moment. (NURSE 13)

Regarding my assistance to the families of children in Palliative Care in the terminal phase, it is aimed at providing emotional support and comfort to family members, especially mothers undergoing the anticipatory bereavement phase. They are the ones who, most of the time, are beside the children at the moment of departure [...]. (NURSE 15)

Category 2 - Orientation provided to the family, valuing their presence and inclusion in the assistance of children with cancer in Palliative Care to promote a peaceful end of life

The category 2 highlights the importance of orientation to the families of children with cancer in Palliative Care in the final stage of life, as well as the appreciation of the family members' presence, especially the mothers' presence, in the process. It also highlights the need to include the families in the care provided to the children, since this relevant assistance action allows them to experience the last moments of their loved one's life with closeness and contribute to a peaceful departure, as the following reports indicate.

I also try to include the families in the care provided to the children, especially the mothers. Valuing the families' presence with the children in their last moments is very important for them and certainly contributes to the children's peaceful death. (NURSE 1)

During the time I have been assisting the families of terminally ill children in Palliative Care, I have always considered the presence of parents and loved ones with them to be valuable [...]. I always try to engage their mothers in the children's care process

until their last moments, since they are usually the ones who are at the children's side at all times. [...]. (NURSE 2)

During my shifts, I always try to guide the parents, especially the mothers who are always with their son or daughter from the beginning of the illness until the last moments of the child's life [...]. I value the parents' presence with the child in the final stage of life a lot because, despite their suffering, they want to be present so that their child can have a peaceful death. (NURSE 5)

I also try to include their families in the assistance I provide [...]. Most of the time, the mothers are the ones who accompany the children [...]. I am always available to guide them, to answer their questions, to invite them to participate in the assistance provided to their children, and to offer them all the support needed so that they can be present when their children depart, so that the children may die in peace. (NURSE 9)

I try to engage the families in the care provided to their children, especially mothers since they have the opportunity to be closer to their children. In addition, I always try to encourage the presence of family members when the children are in their final stage of life since the families want to be close to their loved ones so that their children can have a more serene and peaceful departure, although it is very difficult and sad for every family [...]. (NURSE 11)

I always guide the family members of children with cancer in Palliative Care in the final stage of life. In my opinion, we cannot dissociate ourselves from the nursing care directed to the families without including them with the children in the terminal phase. [...]. The presence of family members is very important so that they can say goodbye to their loved ones and they can die in peace. (NURSE 12)

I always guide parents as to their presence's importance during this phase of their children's lives, however difficult it may be, since their presence favors a calmer end of life for their children [...]. I provide these guidelines mostly for the mothers because most of the time they are the ones who accompany their children until the moment of departure. (NURSE 14)

DISCUSSION

The process of dying involves the patient's increasing loss of bodily functions. In face of this, families can experience this process as a distressing and painful moment. Therefore, the nurses must develop skills that can help the patients and their families to avoid the intense and unnecessary suffering, bearing in mind that families experience worry, fear, and sadness,¹³ especially in the face of the possibility of anticipatory bereavement of their loved ones. The nurses' speeches expressed in category 1 emphasize the professionals' concern in offering comfort to the families, through emotional support in the face of the anticipatory bereavement experienced by the families. The Peaceful End-of-Life Theory includes the bereavement care provided to the people involved in patient care, especially the family caregiver. Bereavement and mourning are considered to be part of an individual's normal and expected reaction to the loss of a loved one, which may lead to psychological and physiological reactions that manifest themselves after the loss.¹⁴ Anticipatory bereavement, in turn, usually arises from the discovery of a diagnosis of an incurable disease, which includes suffering that precedes a loved one's death. This type of grieving is felt by the patients who are in the final stage of life, by their family members, friends, and caregivers¹⁵. This study highlights that the evaluation and treatment of anticipatory bereavement should be part of any Palliative Care model for patients who are terminally ill. It should be emphasized that the proper evaluation and management of emotional problems cannot be ignored, especially the Palliative Care needs of family members, including the anticipatory bereavement phase, in which assistance should be provided to them regularly. Bereavement and mourning

support should include periods before and after the death of loved ones.¹⁶ Therefore, healthcare professionals, especially nurses, should promote assistance based on strategies that seek to provide comfort, guaranteeing dignity and respect for the families of children who experience the finitude process.¹⁷ In the case of nursing assistance directed towards anticipatory bereavement, the Peaceful End-of-Life Theory proposals prioritize the promotion of comfort to the families of patients in the final stage of life.¹³

It is worth noting that comfort is one of the EOL Theory's concepts, which was prioritized during the nurses' speeches, presented in category 1. For this theory, comfort is supported by three pillars, namely: discomfort relief, relaxation, and satisfaction. These principles are vital for the promotion of relief and well-being to the families of children who are terminally ill since comfort contributes to a state of tranquility, mediated by comfort and encouragement, which allow the families to experience peaceful contentment.¹³ Patients diagnosed with life-threatening illnesses and who are terminally ill in their majority wish to be accompanied by their families or loved ones. In this sense, among the principles of Palliative Care, patients' families should also receive support from the multi-professional team, since the involvement of family caregivers, throughout the illness of loved ones until the bereavement process, entails physical, emotional, social, and financial burden.^{2,3} This research emphasizes that the promotion of comfort through the support, understanding, involvement, humanity, and love that these professionals offer to patients' families enables them to face the end of their children's lives, thus favoring a dignified and peaceful death of their loved ones.¹⁸ It was noted in this category that the nurses, in their reports, reaffirm important concepts contemplated in EOL Theory, such as comfort. Thus, the relevance of nursing care directed towards the families of children with cancer in Palliative Care in the final stage of life and during the process of anticipatory bereavement is emphasized.

The EOL Theory regards closeness to people who care for the patient as an essential concept of nursing care provided to patients who are terminally ill since it allows them to experience greater proximity to their relatives, friends, and/or people who care for them.¹⁰ In this context, the nurses' reports contemplated in category 2 emphatically demonstrate the importance of valuing the families' presence during the final stage of life of children with cancer in Palliative Care in order to provide a peaceful final stage of life to their loved ones. The findings of this study corroborate those found in research carried out in Bahia, Brazil, aiming to analyze the multi-professional team's perception of end-of-life comfort in intensive care. In this study, the professionals emphasized that they value the families' closeness during their loved ones' terminal phase, represented by the full-time visit extension.¹⁷ A research carried out in Ohio, United States, with the aim of assessing parents' perceptions of their child's end-of-life care experience and satisfaction with care, found that most parents were satisfied with the care they received, especially with regard to feeling respected; receiving honest communication from the team; spending more time with their child during their last moments of life.²⁰ According to the Peaceful End-of-Life Theory premises, patients and their family members should receive nursing care with an approach to orienting those close to them; promoting the family members' physical presence and participation, so that they become participants in the care process if needed; alleviating the negative feelings of patients and those close to them, such as concerns and doubts; and promoting opportunities for family intimacy.¹³

The reports of some nurses, exposed in category 2, highlighted the concern to provide guidance to family members of children with cancer in Palliative Care in the final stage of life, particularly to mothers. Such reports demonstrate compliance with one of the Peaceful End-of-Life Theory's premises, which is to offer guidance to patients and to the people who are close to them. When faced with their loved ones' finitude, families can experience distressing and painful moments permeated with fear, worry, and sadness. Therefore, the emotional support provided by nurses to inspire confidence and offer guidance in practical matters includes experiences directly

related to being at peace: one of the most important concepts of the Peaceful End-of-Life Theory.¹³ The nurses, as members of the multi-professional team, have expressive participation in the care directed to the families of patients with life-threatening illnesses and who are in the terminal phase, since they are the professionals who are in constant contact with those patients' families. The study evidenced that the positive experiences described by parents of children in the terminal phase have been more often related to family support: humanity, engagement, understanding, and love provided by the assistance teams.²¹ Another study emphasized that family members facing the death of their children in the face of a life-threatening condition have a strong need for compassionate professional support.^{20,21} The findings of the aforementioned research are additional to those found in some studies, in which the parents' partnership in care, communication, relationship with the team, and bereavement support emerged as the main theme related to care satisfaction.^{21,22,23}

Therefore, the nurses' conduct and responses when providing care to children with cancer in Palliative Care in the final stage of life can have a significant impact on the family experience and their memory of the child's death.²⁴ The statements expressed in category 2 highlight that during nursing care provided to families of children with cancer in Palliative Care in the terminal phase, nurses develop courses of action that address two fundamental concepts of the Peaceful End-of-Life Theory: closeness to loved ones and the experience of peace. The EOL Theory presents premises that converge with the Palliative Care philosophy, which aims to provide an integral and humanized assistance to patients, from the diagnosis of a threatening disease to the continuity of life until its end and offer support to the families throughout the entire illness process including the bereavement phase. Therefore, this theory is undeniably important to support the clinical practice of nurses directed to patients in the final stage of life and their families.

CONCLUSION

The study findings reveal that the courses of action reported by the nurses regarding their performance reflect their commitment and sensitivity in two moments: when providing assistance aimed at comforting the families facing anticipatory bereavement of their loved ones; and when highlighting the importance of family members as participants in providing care, promoting a peaceful end of life for the children with cancer in Palliative Care. Such findings contemplate concepts of the Peaceful End-of-Life Theory. This study's findings contribute to the nursing field, to the pediatric oncology field, and to the Palliative Care context. The EOL Theory's relevance and application to support the nurses' care practice when providing care to children with cancer in the end-of-life stage, with emphasis on the families, are highlighted. Given the above, it is hoped that this study can contribute to new investigations and give rise to reflections in the field of nursing care and teaching. This study's limitations are related to the reduced quantity of publications on the subject researched in national and international literature, especially works that used the Peaceful End-of-Life Theory, which indicates the need for new research on the subject.

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