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PALLIATIVE CARE FOR ONCOLOGICAL CHILDREN: FEELINGS OF THE NURSING TEAM

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ABSTRACT

Introduction: Palliative care is an agglomerate of actions that promote comfort, whether in the hospital environment or at home to the individual without therapeutic possibility. **Objective:** To understand the feelings that are aroused in the nursing team professionals dealing with oncology children in palliative care. **Materials and Methods**: The research was carried out at Hospital São Marcos, which is a reference center for cancer treatment, located in the south central region of Teresina, Piauí. The research participants were ten professionals from the nursing team who work or who have already worked directly with oncological children with no possibility of cure. **Results:** After analyzing the statements, two categories emerged entitled: "Feelings of nursing professionals who assist oncological children: interferences in palliative care", whose content reveals the feelings that are aroused in the team; and "Strategies used by the nursing team to promote palliative care in oncology children in the terminal phase", which reveals the duties of the team in caring for terminally ill children. **Conclusion:** At the end of the research, we can observe a humanistic team that always seeks the best for the patient, regardless of the feeling that is aroused in the professional caregiver.

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INTRODUCTION

The child, when diagnosed with cancer, goes through a period of transition and denial due to the severity of the disease, which has a very strong link with death. The family and the child will begin to adapt to a new reality and there will be changes in the family and social sphere, such as social isolation, attending less public places and interrupting the performance of their routine activities (Silva; Cabral; Christoffel, 2010). Children diagnosed with childhood cancer are very distressed, as they perceive the shock and sadness experienced by their family members, even though they do not understand the risks that the disease and the hospitalization process will trigger in themselves and in everyone involved. Many changes will appear in their routine and in the dynamics of their family, causing a rupture and distancing from their

social environment, changing the daily life. The dynamics of the patient and their family will revolve around hospital treatment and routines, such as frequent appointments with doctors and daily interventions by countless health professionals. The uncertainties that arise with the diagnosis of the disease trigger, mainly in parents, feelings such as guilt, anguish, anger, fear and an overwhelming doubt about the cancer prognosis, involving the possibility of cure or the certainty of the death of their loved one. There is a variation of sensations that go beyond the feelings that are generated in everyone involved, covering a whole moral, social, psychological set, bringing much suffering and expectations (Monteiro *et al.,* 2008). During cancer treatment, the child may not respond to chemotherapies, radiotherapies, and medications in general. After the team of health professionals together with the parents have tried all the possibilities of curing the patient, he or she will be considered as out of the possibility of cure, in which the nursing professionals will start a new conduct known as palliative care (Carneiro; Souza; Paula, 2009). The main objective of palliative care is to add quality of life to the days, not to increase the days of life. This represents a great challenge for the nursing team, which should prioritize the valorization of this care (Waldow; Borges, 2008). Therefore, the nursing team that works in palliative care should perform them from a humanistic view, favoring the strengthening of emotional bonds between professionals, children and family members, even in the face of the impossibility of curing the patient.

Caring for children with no possibility of cure in oncology is quite difficult, since the nursing team often cannot deal with death and dying as a possibility for the end of the life cycle. Consequently, it is the moment when the child needs more care and attention and the nursing team professionals are not always prepared to deal with this situation, revealing a moment of great vulnerability in the face of losses. Thus, these professionals in the face of these painful experiences need to seek the restoration of their inner strengths that will be essential to deal with this process (Lopes; Silva; Andrade, 2007). The theme is relevant when considering that we are not properly prepared to deal with the stigma of death. Therefore, understanding the feelings of the nursing team regarding the difficulties found in the care process provided to terminal cancer children is important, in order to plan and intervene with preventive measures in the educational process with this population. Given the above, the study aims to understand the feelings experienced by the nursing team regarding the care of oncological children.

MATERIALS AND METHODS

It is a descriptive and exploratory study, with a qualitative approach. The research was carried out at Hospital São Marcos, which is a reference center in cancer treatment, located in the south central region of Teresina, Piauí. The research participants were ten female nursing professionals (three nurses and seven nursing technicians), among them, eight are single and two are married, aged between 21 and 49 years old. Data collection was performed in November 2016, through a semi-structured interview script, containing closed questions. The interviews were recorded on cell phones, avoiding the loss of information during the statements of the interviewees, ensuring a clear reproduction and allowing analyzes and interpretations of the statements later. After recording the interviews, the statements given by the interviewees were heard and organized using the content analysis technique of Minayo (2010), creating two categories entitled: "Feelings of nursing professionals who assist oncology children: interference in palliative care", and " Strategies used by the nursing team to promote palliative care in oncology children in the terminal phase ". The risks and discomforts resulting from this study were classified as minimal, as the study involved private and subjective issues of the subjects. It is believed that the present study will bring countless benefits both for cancer patients and their families, as well as for health professionals who deal with them, as it will contribute to a greater understanding on the part of professionals, being able to report their feelings and experiences about the theme, exposing their desires. The research was conducted in accordance with the guidelines and regulatory standards for research involving human beings of Resolution No. 466/12 of the National Health Council, which considers respect for human dignity, protection of research participants, development and ethical engagement, among others. The research project was approved in accordance with CAAE 58340816.3.0000.5602.

RESULTS AND DISCUSSION

When evidencing the feelings about palliative care in oncology children in terminal phase, the pediatric nursing team brings with them the most diverse emotions that are aroused in them during care. In this study, two thematic categories will be contemplated: "Feelings of nursing professionals who assist oncological children: interference in palliative care", whose content reveals the feelings that are aroused in the team professionals and "Strategies used by the nursing team to promote palliative care in oncology children in the terminal phase", which reveals the attributions of the team in the care that will be provided to the terminal child.

Feelings of nursing professionals who assist children with cancer: interferences in palliative care

While conducting the research with the nursing team at Hospital São Marcos, one can observe the most diverse feelings that are aroused in nursing professionals by performing the care provided to oncological children without therapeutic possibilities. Countless feelings are aroused, such as grief, sadness, coldness, pain, pity, anguish, impotence and failure in the face of healing, the emotional fragility of professionals in dealing with this overwhelming situation caused by the aggressive treatment and the fatality of the disease.

> [...] I end up getting a little fragile with the situation, but in the course of everyday life, we become a little cold with the situation, because we end up getting used to the rules, routine activities, but even so, we still suffer. We cry hidden. (Nurse I)
> [...] I feel sad for the child and the family who, in such a short time, will lose their child. (Nurse II)
> [...] The feeling is actually incapacity. Knowing that we can no longer do something for that child to heal. (Nurse III)
> [...] Pain and sadness are the main feelings, both for me and for the parents, because here, we are a big family and we, as professionals who live with these children, create a very big attachment. (Nursing technician III)
> [...] The feeling is sadness that I cannot do anything

> else, but we try as much as possible, to give the best for their treatment. (Nursing Technician V)
> [...] Feeling of pain, sadness, pity, and anguish in my heart for knowing that despite all my effort and dedication, I cannot bring a cure to that child, I mean, an angel. (Nursing technician IV)

Death can be understood as a setback, since the priority is to improve the patient towards healing and not death. When the professional is unable to achieve his/her goal, which is to provide procedures that will restore the patients and they die, his/her performance can be seen as a failure. The nursing team, in its plurality, manifests a great deal of discomfort when treating children in terminal stage of cancer under palliative care, because children are seen by society as carriers of joy and life, characteristics that are opposed to death (Andrade; Lopes; Silva , 2007). Analyzing the speeches of the nursing team professionals, we can understand the fragility that the team has in front of the patients without therapeutic possibilities, who need extra attention because they are so fragile, and who still have a long journey to be followed, not understanding the reason for such an overwhelming disease to affect them.

According to Poles and Bousso (2006), death is present in every moment of life and it is in this transformative moment of the relationship that living is established. Although in some circumstances it is not possible to save the child's life, professionals become a key piece for children with terminal cancer and for their family, once both will need care and attention so that they can experience the proximity of finitude with balance and comfort. However, death is inevitable and becomes frequent in the lives of nursing professionals, especially those who deal with traumatic situations with symbolic and real losses. Even these professionals dealing with these painful experiences on a daily basis, it is clear that they have difficulty in accepting the situation in which the patient and his/her family are, as well as conducting their actions in the face of certainty of loss. At the same time that nursing professionals have negative and destructive feelings in the face of failure, loss and death, living with children and their families encourages them by seeing the struggle of these little warriors against such a serious illness and the willpower to live. Joy, hope and satisfaction are feelings generated in this interaction. Compassion and solidarity make these professionals put themselves in the place of each of the little ones, as if that child were a loved one, treating them with empathy, which can be seen in the following statements of the interviewees.

> [...] I feel the satisfaction of monitoring and giving her all the comfort she needs. (Nurse III)
> [...] happiness when I see the child playing, smiling and interacting with me. It's the best sensation in the world. Another feeling that is awakened in me is affection. I confess that living with them, on a daily basis, contributed a lot to my life. (Nursing technician II)
> [...] We, who live with these children every day, end up creating a very special attachment. (Nursing technician III)
> [...] The feeling that awakens in me is hope. There is no way for me to arrive at the workplace every day and look at the child diagnosed with cancer without the possibility of a cure and not see the spirit of hope in him/her. (Nursing technician VI)
> [...] I always put myself in their place and in the family and I have the same feeling as if it were a loved one of mine going through that. I put myself in her shoes. I see myself there. (Nursing technician VII)

There is a great effort by the nursing team to deal with the terminality of children, and this difficulty may be alleviated by professionals with the creation of reflective spaces. On that occasion, these individuals become capable of expressing their anxieties, since day by day matters related to death are not discussed (Costa; Ceolim, 2010). When an oncological child is diagnosed as in terminal stage, he/she will receive palliative care and the team will have to formulate strategies to control the symptoms of the disease. This care aims to alleviate the suffering of the patient, not bringing him/her a cure, but seeking to preserve the quality of life of the sick child until the end of his/her days. Generally, care is focused on hygiene, food, dressings and care for ostomies and attention to analgesia (INCA; 2016). The nursing team has attributions of great importance in providing palliative care aimed at oncology children in the terminal phase, as well as in the acceptance of the diagnosis giving them support to live with the disease. In this way, these professionals develop comprehensive care for children and their families, listening to their fears, suffering, hopes, anxieties and aiming to reduce the anxiety that develops for fear of the disease, which is considered ruthless and makes everyone fear for the future (Nascimento *et al.,* 2013). At the end of this category, it is observed that the professionals of the nursing team, despite showing fragility towards patients out of therapeutic possibilities, are strong and their professionalism is inherent in the face of small human beings who need their care. We can understand from the statements of the interviewees that despite all the suffering, joy is present in these moments of complicity and compassion. In addition, the relief of pain by providing fun moments for children that evoke moments of glory, peace in professionals and the certainty that they did and give their best during the whole period spent together, strengthening and allowing them quality of life.

Strategies used by the nursing team to promote palliative care in oncology children in the terminal phase

In this category, we demonstrate through reports, the strategies that are used by the nursing team in palliative care for oncological children. Analyzing the statements of the interviewed professionals, we observed that the strategies used will always be directed to minimize and relieve the pain and suffering of the patient, as well as educational procedures that involve a multidisciplinary team. This team will work on various activities as a way of entertainment and distraction, in an attempt to convey confidence and enable joy to these children, in addition to other measures that bring comfort and safety to patients, as evidenced in the statements below.

> [...] Palliative means a blanket that is protection and what I offer to the child who is in palliative care. It is my protection against pain, because at that moment, what the child needs is just attention and care, whether from the team or the family. Our role is to provide the greatest possible comfort for children while they are alive, which means to offer quality of life for these 'angels' while they are with us. (Nurse I)
> [...] Of the strategies used, the main one is pain relief. So the main care that we provide to the oncological

child is exactly the control of pain, being performed to give comfort to the children. (Nurse II)

[...] In addition to the nursing team, we have a multiprofessional team, which performs from educational procedures to procedures that will minimize the child's suffering, always trying to offer better comfort to the child. (Nurse III)

[...] Always relieve the child's pain, because despite being palliative care, it is not necessary for the child to suffer. Whenever I can, I try to play with them a little and when I can't, I communicate to the occupational therapist to do some activity. (Nursing technician I)

[...] I always try to be happy with the child and the parents. Always talking and motivating the family to offer the best possible comfort for their children. (Nursing technician III)

[...] I try to offer happy moments while the child is alive, without forgetting, of course, to provide special comfort for them, with the use of pain relief medications, massages and games. (Nursing technician VI)

Professionals recognize that drug treatment is very important for the relief of pain and suffering, but that joy and attention are fundamental elements to face this situation. For Moritz et al. (2008), the nursing team must establish the fundamental principles of palliative care that will be provided for the acceptance of death in a natural way, both for the child and for the family, giving priority to the patient's needs, avoiding curative therapeutic measures, which will not bring any benefit, leaving the patient frustrated.These measures should provide a better quality of life for patients, relieving not only their pain, but treating them holistically and respecting their autonomy. All actions must be planned by the nursing team together with the entire multidisciplinary team. In addition to the interrelationship with the teams, there must be effective communication with the patients and their families, making them aware of each procedure performed, each benefit achieved, providing them, gradually, a good quality of life until the decease moment. The nursing team professionals are the people closest to the patient and their family members, sharing a variety of feelings about suffering and death, and therefore, they need to be prepared to care for the terminally ill patient. The refusal to heal in order to take care does not imply failure, but an acknowledgment of the limits of the technique. Thus, it is necessary to deal healthily with the inevitable events of the disease and with the last moments of life. According to the statements of the interviewees, we note that the main tools that are directly related to a favorable care for an oncological patient is to minimize the suffering experienced through the prescribed medications, comfort massages, bed bath, oxygen supply and dressings. When the patient reaches this terminal stage of cancer, they tend to experience very severe pain, where other comfort measures become dispensable if they are unable to stabilize the suffering caused by the severe pain, as reported in the speech of the participants.

[...] The main care that we provide to the oncology child is exactly the control of pain, with care being performed such as: bathing in the bed, offering oxygen, dressing, assessing the risk of falls, risk of ulcers, by pressure. (Nurse I)

[...] I always look for strategies to relieve their pain through the prescribed medications and I always try to make the changes in decubitus to offer a better comfort for them. (Nursing Technician II)

[...] I give medications at the right time to never leave my little angels in pain. (Nursing Technician III)

[...] The terminally ill patient usually feels a lot of pain and both I and the team try to do our utmost to try to reduce this pain with the use of medicine in them. (Nursing Technician IV)

[...] Special comfort for them, with the use of pain relief medications, massages and games. (Nursing Technician VI)

According to Monteiro, Rodrigues and Pacheco (2012), the nursing team is concerned with minimizing the suffering of the patient by relieving the pain that is a peculiarity of the oncological disease, using actions that enable continuous activities provided to oncological children. These actions provide comfort measures that are developed based on the needs of the patient and the family context in which it is inserted. The nursing team is part of the palliative care process, which is essential in the fight against pathology by children and their families. In this way, the nursing team has a major role in the care that will be provided, such as accepting the diagnosis and daily support for children and family members to be able to live with the disease in a less painful way (COSTA; CEOLIM 2010). The comfort of patients is a conduct that constitutes their well-being, whether physically or psychologically. Regarding the care provided to the child diagnosed with terminal cancer, this conduct is inserted in the care provided by the nursing team, always prioritizing the protection and restoration of the strengths of the patient and family (CARNEIRO; SOUZA; PAULA, 2009).

When providing care to children with terminal cancer, in addition to incorporating the care of curative therapies in monitoring pain and symptoms, support for the family is essential. Mainly because the diagnosis of cancer causes great shock to the patients and their family, because it is a disease that will potentially cause death and its treatment will occur in a long way. This is quite exhausting for everyone involved, where sometimes the treatment will not bring satisfactory results, causing the child to receive palliative care (COSTA; CEOLIM 2010). From the analysis and discussion of the speeches, it was possible to observe that caring for the child with cancer under palliative care is a process of great suffering for the patients and their family. In the perception of professional caregivers, the primary tactic in the search for a more humane care directed to palliative care is basically the realization of strategies that offer comfort, educational actions, affection and attention aimed at the terminally ill child. In this sense, the performance of the nursing team is essential to provide the best possible use of the time that this child still has.

Conclusion

At the end of the research, we can observe a humanistic team that always seeks the best for the patient, regardless of the feeling that is aroused in the professional caregiver. In this sense, when analyzing the statements of the interviewees, we noticed a humanist view of nursing technicians, since these professionals, who have greater contact with oncological children, create a stronger bond with them and their families. These members of the nursing team spend most of their time inside the hospital. However, nurses also have a very

significant share in providing palliative care. They, together with the multiprofessional team, aim to plan and promote the care that will be provided to the child and the family, giving them quality of life for the remaining days and not adding days to life. In view of the research, we can highlight the relevance of this study in contributing positively to the care provided to the child, making the nursing team reflect much more about the importance of palliative care, emphasizing the quality of life of children while they are alive and always offering all possible support for their families, as well as developing humanized acts involving sensitivity with love and compassion for others.

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