

# Palliative care in pediatric oncology in nursing students' perception\*

*Cuidados paliativos em oncologia pediátrica na percepção dos acadêmicos de enfermagem*

*Cuidados paliativos en oncología pediátrica en la percepción de estudiantes de enfermería*

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## ABSTRACT

**Objective:** To know the perception of Nursing scholars about palliative care on pediatric oncology. **Methods:** Exploratory research with qualitative approach held on 2014, in a School of Nursing at Universidade Federal do Rio de Janeiro. Were interviewed 20 undergraduate students in their senior year. The data collected were submitted to Thematic Analysis. **Results:** For the students, the palliative care in pediatric oncology is associated to controlling signs and symptoms related to diseases' progression, comfort, support, promotion of quality of life and well-being, using recreational resources. On the other side, some understand that palliative care aims to prolong life. They perceive the need of a multi-professional team acting together with the child and their family. **Conclusion:** Considering the complexity and multiple aspects involved in palliative care, the same must be approached during Nurses' undergraduate course.

**Keywords:** Palliative Care; Oncology Nursing; Child Health.

## RESUMO

**Objetivo:** Conhecer a percepção dos acadêmicos de enfermagem sobre cuidados paliativos em oncologia pediátrica. **Métodos:** Pesquisa exploratória, abordagem qualitativa, desenvolvida em 2014, na Escola de Enfermagem de uma Universidade Federal no Rio de Janeiro. Realizada entrevista semiestruturada com vinte acadêmicos do último período da graduação. Na análise dos dados emergiram duas unidades temáticas: percepção dos acadêmicos quanto aos cuidados paliativos em oncologia pediátrica e quanto à atuação da equipe profissional. **Resultados:** Para os acadêmicos, os cuidados paliativos em oncologia pediátrica estão relacionados ao controle de sinais e sintomas, conforto, apoio, promoção da qualidade de vida e bem-estar. Por outro lado, alguns entendem que o cuidado paliativo tem como objetivo prolongar o tempo de vida. Percebem a necessidade da atuação da equipe multiprofissional junto à criança e sua família. **Conclusão:** A complexidade e os múltiplos aspectos envolvidos no cuidado paliativo exige que o mesmo seja abordado durante a graduação dos Enfermeiros.

**Palavras-chave:** Cuidados Paliativos; Enfermagem Oncológica; Saúde da Criança.

## RESUMEN

**Objetivo:** Conocer la percepción de estudiantes de Enfermería acerca de los cuidados paliativos en oncología pediátrica. **Métodos:** Investigación exploratoria, cualitativa, realizada en 2014, en la Escuela de Enfermería de la Universidade Federal do Rio de Janeiro. Fueron entrevistados 20 estudiantes del último período del curso de gradución. Los datos fueron sometidos al Análisis Temático. **Resultados:** Para los académicos, los cuidados paliativos están relacionados con el control de los signos y síntomas de la progresión de la enfermedad, comodidad, apoyo, promoción de calidad de vida y bienestar con el uso de recursos recreativos. Por otro lado, algunos creen que estos cuidados tienen como objetivo extender la vida útil. Se dan cuenta de la necesidad de un equipo multidisciplinar para actuar junto a los niños y sus familias. **Conclusión:** En vista de la complejidad y de los múltiples aspectos involucrados en los cuidados paliativos, el mismo debe ser abordado durante la graduación.

**Palabras clave:** Cuidados Paliativos; Enfermería Oncológica; Salud del Niño.

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## INTRODUCTION

Cancer is a group of diseases that have in common the uncontrolled proliferation of abnormal cells that invade tissues and organs and may spread to various parts of the body, causing metastases<sup>1</sup>.

Considered a rare disease, the children's cancer, that is, the one that affects children and adolescents between 0 and 19 years, corresponds to 1% and 3% of all malignant tumors in most populations. In Brazil, the cancer occupies the second position of deaths of children and teenagers (0-19 years), losing only to deaths by external causes, configuring it as the disease that kills the most in the country<sup>1</sup>.

The pediatric cancer, when diagnosed early and treated in specialized centers, have a chance of cure around 70%. However, when possibilities of curative treatment -ranging from surgery, radiotherapy, chemotherapy and even transplant - run out and the disease does not regress, only comfort measures at this time of inability to cure are left. So, the proposed treatment becomes palliative<sup>1,2</sup>.

The World Health Organization (WHO) defines palliative care "as an approach that aims to improve the quality of life of patients and their families, which are facing problems associated with diseases that threaten life. Achieved through the prevention and relief of suffering, through early identification, assessment and treatment of pain and other problems of physical, psychosocial and spiritual orders"<sup>3</sup>.

Palliative care in pediatrics are those that seek to improve the child's quality of life by relieving pain and other physical symptoms, as well as supporting the spiritual and psychosocial needs and expectations of the child and family, since it needs support at the time of grief<sup>3</sup>.

The role of the nurse begins on the moment of giving the news to the family and the child, depending on their age and their ability to understand what is being said, until the moment of supporting the grieving of the family. The professional should promote a care centered on the child's particularities, in addition to establishing communication with the family, which is an essential component in health promotion and in the care of the child, with full assistance, which includes biological, psychological, social, economic, spiritual and cultural aspects<sup>4,5</sup>.

For the full assistance that the phase of palliative care requires, it is necessary academic training that cover this issue. However, the scientific literature suggests that in the training of health professionals, there is still a predominance of biologist logic. The scientific evidence on the need to prepare the graduate to face death show that the curriculum in higher education institutions in the health area have not yet assured the contextualization of the theme in a consistent way<sup>6,7</sup>.

In scientific literature, there are currently studies focused on professional staff, that sought to analyze the behavior of

nurses in care before the child without possibility of cure; as well as describing the perceptions and experiences of the nursing staff in relation to the family in palliative care in oncology and understanding the significance for the nursing team to take care of children with oncological diseases without possibility of cure<sup>4,5,8</sup>. However, there are few references and research that cover the perception of students, more specifically those of Nursing, future health professionals, as for palliative care developed with the children with cancer and their families.

Based on the exposed, this research had as object of study: palliative care in pediatric oncology in the perception of nursing students. Thus, the guiding question of the study was: What is the perception of nursing students on palliative care in pediatric oncology? For which, it was established the following objective: to know the perception of nursing students on palliative care in pediatric oncology.

## METHODS

This is an exploratory research, with qualitative approach<sup>9</sup>, held in a Nursing School of a Federal University located in the State of Rio de Janeiro. Theoretical content on oncology and palliative care in Pediatrics are offered at the 7<sup>th</sup> graduation period, in a mandatory discipline that addresses the health of hospitalized children. In the curriculum, there is also an elective discipline on oncology, but that does not address the subject. All the academics experienced the university hospital, scenario in the theoretical and practical teaching, however there is no assistance for children with cancer.

Twenty scholars from a class of 33 nursing graduate students in the ninth period, that is, the last one of undergraduate nursing, participated. The academic participants of the study represent 60% of the ninth period of class.

The inclusion criteria for participating were: be a student aged over 18 years, attending the last graduation period. The criteria for exclusion of participants were: academics with registration locked during the data collection period, and academics who work as nursing technicians, since they can bring practice experiences that have not been acquired in the undergraduate course.

The number of participants was enclosed in the course of research and interrupted when there was saturation of data. The criterion of saturation is defined as the knowledge gained and that can understand the internal logic of the group or collectivity study.

The data were collected through semi structured interview, conducted from September to November 2014. Were open-ended questions, in which the respondent had the opportunity to talk about palliative care in pediatric oncology, namely: What do you think on palliative care in pediatric oncology? How do you think is made palliative care for children with oncological

diseases? What are the palliative care that a child with cancer illness demands? The closed questions were used to identify the participants.

The interviews, with approximate duration of 30 minutes, took place in scheduled date and time, according to the availability of the participants. To ensure privacy and prevent noise interference during recording in electronic device (MP3), the interviews, which were conducted by the first author of the article, occurred in empty classrooms of the Nursing School.

The interviews were transcribed verbatim and analyzed according to the three stages of Thematic Analysis<sup>9</sup>: (1) pre-analysis, with floating reading to know the content of empirical material generated by the interviews; (2) the exploration phase of the material, when the raw data were transformed into units representing meanings and then aggregated in categories; (3) treatment phase and the interpretation of results, when it was possible to make inferences in the light of the scientific literature on palliative care in nursing students' perception.

The study was approved by the Ethics and Research Committee of the institution where it was held (CAAE: 33739514.4.0000.5243/Opinion: 751,462), and complied with all aspects contained in Resolution 466/12 of the National Health Council. In this sense, the participants signed two copies of the Informed Consent (IC), one copy stayed with the researcher and the other, with the participant. It was guaranteed anonymity of the participants through the classification of these in numerical order preceded by the letter "A", referring to the academic.

Any material obtained through the collection of data, such as voice recording and transcript of the speeches, will be stored by the researcher for a period of 5 (five) years and then will be destroyed.

## RESULTS

From the analysis of the responses of the academics interviewed, emerged the following thematic units: perception of the scholars regarding to palliative care in pediatric oncology and perception of the scholars regarding to the performance of the professional team in the implementation of the palliative care.

### Perception of the scholars regarding to palliative care in pediatric oncology

In the perception of nursing academic students participating in the research, palliative care in pediatric oncology intend to relieve symptoms, as well as provide comfort and well-being for the child. It should also be noted that, for some participants, this care aimed to extend the lifetime of patients.

Nursing academics highlighted that this type of care is carried out in order to relieve the symptoms, such as pain, respiratory distress, difficulty in feeding and locomotion, in addition to the identification of any complication. For this, medicines and non-

pharmacological measures are used, such as applying hot and cold compresses, and monitoring the vital signs of the children.

*I think the palliative care is made through medication, radiotherapy and chemotherapy [...] Bathing, check vital signs, if the child has some complications. Trying to solve the problem (A9).*

*Ah, the palliative care that a child with cancer disease demand, are the general care a child without any pathology requires, as pain relief (A8).*

*Even with treatment with hot/cold, compresses, things to ease the pain and suffering of this child (A16).*

*I think the pain is the main, but I think depending on the area that the child is compromised may cause breathing problems, difficulty in feeding, in locomotion. It is even, not only on the locomotion, but also in cognitive, child's mental (A17).*

For most of nursing academics, palliative care offered to children with oncological disease do not have to aim only the relief of pain and physical symptoms, but also the promotion of well-being and mental health through activities and playful games, approaching the family, giving psychological support, social interaction and promoting activities that elevate the self-esteem of the child. For this, they reinforce the importance of a pleasant atmosphere, being adapted to the needs that are specific to childhood:

*Besides the issue of care, as pain relief, comfort provider and improving the child's quality of life, it has all the playful question, right? Just do activity with these children, care will improve its self-esteem and, consequently, will influence their clinical situation, right? (A10).*

*The child demands care with recreation and growth. As much as you know that they have little time to live, you have to provide that they have the rest of the time to live happy and without pain, right? Being a kid. (A13).*

*Palliative care come with the proposal of relieving the suffering of the child, giving support to the family and to the patient, in order to enable a more peaceful death, in a way of saying. Mitigating signs and symptoms, such as pain, for example. (A20).*

For other academics palliative care in pediatric oncology is used with the purpose of prolonging the child's lifetime:

*Palliative care will be able to extend the life of children, causing her to have that last bit of life, right? (A2).*

*Well. I think it is the same care you have with adult patients, that through therapeutic treatment, we try to extend as much as possible the life of this child (A9).*

*The maximum of estimate, huh? Prolonging this life for him to stay here for a period more, got it? (A6).*

### **Perception of the scholars regarding to the performance of the professional team in the implementation of the palliative care**

Academics participants of the research talked about their perception on the work of professionals in palliative care. In this regard, they stressed the importance of the multidisciplinary team and that everyone should act providing support to the children and their families.

Respondents emphasized the importance of the work of the multidisciplinary team for achieving success in the care of the child with cancer disease with no chance of cure:

*Well. I think this child needs psychological attention, huh? Nutritional care, because of the medications, radiotherapy and chemotherapy that are made in the child, and the general care of nursing (A9).*

*I think it is a super important area, not only for the people who work with nursing, but also for the multidisciplinary area of health. I think that it is an area that requires greater knowledge about Oncology, about this type of care (A17).*

Some respondents talked about the importance of the role of nurses with the children, providing support and guidance, clarifying the changes that occur in their body, why they are hospitalized and will need to return to the hospital, the side effects of medications and the limitations to the practice of some activities.

*You have to give support to the child. Make that child become active in the treatment; to understand what is happening, what is being done. [...] Talk about the changes of the body that the child is going to have, you know? (A1).*

*We can make use of toys and drawings for them to express their feelings. They need to have something to relief the pain they are feeling right now (A16).*

*Talk to the child so it can understand the reason for being, why it cannot return home, why it must often return to the hospital, why it get sick with the drugs, why it cannot do certain activities. (A19).*

Some scholars emphasize the importance of the family in palliative care in pediatric oncology. They stressed the need to offer support to parents so that they can provide safety to the child and calm them during this process, being involved in care and receive guidelines for the care of the child:

*How parents face this moment. [...] The professional also has the thought focused on the parents (A8).*

*When I think of palliative care in pediatric oncology, I not only think on the child, but also in its family. Because just as it is very difficult for the child, its support is the family, which will also face this in a very complicated way. So, the family is the focus of our care (A19).*

## **DISCUSSION**

Through the testimonies of the participants of the survey, it was possible to observe the concern with the control and elimination of signs and symptoms during palliative therapy, especially the pain. It is noteworthy that the literature refers to pain in palliative care, not just as physical pain caused by the tumor, but also as a reflection of the situation that the patient lives, including the physical, mental and spiritual aspects<sup>5</sup>. In this sense, the future professionals need to be sensitized to understand that the evaluation and control of pain is something complex, which requires effort and commitment of the multidisciplinary team.

Success in pain control depends on a rigorous evaluation of its intensity and effectiveness of analgesics used. For this, it is essential to understand child development and behavior, because many times the child is too small to express, through speaking, everything its feeling. Therefore, it is important to know the parameters of signals for certain age groups, in order to determine variations in manifestations of pain<sup>10</sup>.

Several instruments can be used for the assessment of pain in Pediatrics. These include interviews, for children that can verbalize and describe the pain, and scales that take into account aspects of behavior, such as the position of the body, facial expression, crying; and physiological, as heart rate, sweating, and respiratory rate, among others<sup>10</sup>.

Academics participants of the research also reported the need for control of other signs and symptoms, such as respiratory discomfort, difficulty in feeding and locomotion, which are recurrent in the child in palliative care, whether by the advancement of the disease, or by the use of medications.

It is important that nursing professionals be qualified to intervene in these most common clinical symptoms in terminal illness, to act more promptly and properly use medications to control symptoms<sup>5,11</sup>. As most frequent signs and symptoms,

the highlights are: dehydration, constipation, fatigue, weakness, nausea, vomiting, cachexia, infection, anemia, endocrine and metabolic changes, muscle changes, mucositis, dyspnea and altered mental status<sup>5</sup>.

Academics have highlighted non-pharmacological measures with the aim of ceasing the symptoms at this stage. The literature suggests that several non-conventional therapies are currently used in the treatment of various harms to health, including aromatherapy, play therapy and therapeutic touch<sup>4,11</sup>.

It was highlighted the importance of preserving the children's environment, emphasizing the play. Thus, giving possibilities and stimulating games with children in palliative care is to recognize the specificities of childhood, since it is through playing that children communicate and express their feelings, anxieties and frustrations. In this context, several resources can be used to minimize illness and hospitalization, and still promote the well-being, comfort and joy, such as drawing, painting, music, toy, theatre and storytelling<sup>2</sup>.

Some scholars perceive palliative care as a strategy to prolong life. Such mistaken view indicates the need for greater approach to the subject during graduation, to clarify the objectives and better understanding of the philosophy of palliative care, as for children without possibility of recovery, the use of healing interventionist measures end up being major complicating factor in palliative care, because not only they are costly and without benefits, they generate only pain and suffering<sup>12</sup>.

There is, on the part of health professionals, difficulties in the management of children in final stage of life, which refer to the wrong choice of prolonging life rather than the indication of palliative care. This behavior of health professionals is justified by the lack of education and training to deal with the issues involving the end of life in graduate and postgraduate education, such as bioethical fundamentals, communication skills, care strategies and lack of discussion of palliative care, although these have already been elected by the World Health Organization as a priority for more than a decade<sup>13</sup>.

The National Curriculum Guidelines (NCD) calls for the formation of a generalist nurse, humanist, critical and reflexive, to act on the social reality and meet the population's needs with responsibility and commitment to citizenship and comprehensive health of the human being. In this sense, the expected profile shows, among other features, the ability to recognize and intervene on the different problems and situations of the health-disease process, with identification of bio-psycho-social dimensions<sup>14</sup>. As part of palliative care, these dimensions must be addressed in order to offer comfort and well-being to the days of life to people without possibilities of healing, including children with cancer.

As for the performance of the team, the scholars highlighted that it is fundamental the multidisciplinary work in the assistance for the child with cancer disease without therapeutic possibility. In this sense, there is a study that was conducted in order to understand the vision of the multidisciplinary team towards the child with leukemia in palliative care. Participants pointed out that, for palliative care to be developed safely and satisfactorily, it is necessary that in multidisciplinary team work all have aligned attitudes, regardless of the professional category. In addition, all should promote integral assistance to individuals and their families, always respecting their beliefs and opinions<sup>15</sup>.

In this sense, it is also important to create spaces for discussion among the professionals of the team so that the issues that emerge during the work process are addressed<sup>6</sup>.

Concerning the actions with the child, it is worth highlighting the importance that communication, whether verbal or non-verbal, has in relation to the child who experience the terminally process, because it is considered the foundation of a good interpersonal skills, in pursuit of their well-being. Through communication, the team shows itself available to be with the child, understand it and help it<sup>16</sup>.

It is essential to give voice to the child and establish an open and frank relationship to understand its experience and thus develop assistance in all its fullness, based on palliative care, guided by the showing of warmth in attention and sensitivity to be present for soothing and comforting the child<sup>16</sup>.

With the established communication, it is possible to exchange information between the professional and the child. In this sense, a study points out that nurses have an important role to play in guiding the child by making it an active and participative subject in its care<sup>17</sup>. This exchange of information also favors the selection of the most appropriate interventions for each child<sup>5</sup>.

It was also observed that scholars have cited that the family should be involved in palliative care to children with oncological diseases with no chance of cure. This perception is in line with what is recommended by the World Health Organization<sup>3</sup>, where family support is paramount in this very painful process.

To live the experience of having a child facing this situation, the family disrupts emotionally and goes through moments of great fragility and vulnerability, requiring a support to face this time. In this sense, the support to the family and to the child can occur through a conversation, a hug, to ease the painful moments and fears that emerge before the worsening of the clinical condition and the imminence of death<sup>4</sup>.

It is important to preserve an effective communication with family members of children in palliative care, because this has paramount performance in promoting the well-being of the

patient<sup>18</sup>. In a study with family members who are caregivers of these children, they reported that throughout the course of the disease process, communication between the health team and the family proved to be confusing and ambiguous. Therefore demonstrated, the need to get real and objective information about the child's health. It was found that the proper communication could assist them in the acceptance of death<sup>19</sup>.

The aspect of spirituality, which is contemplated in the definition of palliative care from the World Health Organization, was not mentioned by any of the research participants. This finding demonstrates that spirituality needs to be better worked, especially in palliative care, offering individualized care, because it is through it that people look for comfort and meaning to face the difficulties<sup>5,20</sup>. In research which objective was to investigate the experience of family in the caring of children and adolescents with cancer in palliative care, the family members pointed out faith and religious and spiritual belief among the most important and necessary support to facing the illness and death process<sup>19</sup>. It is up to health professionals to promote an environment that encourages the child and their family to develop their spirituality and religiosity.

## CONCLUSION

In the perception of most nursing students interviewed, palliative care focused on children with cancer involves measures employed to control the signs and symptoms that appear when the disease does not have a chance of cure. In addition, it aims to promote comfort and support, using play activities to promote physical and mental well-being in child care, which favors the improvement of their quality of life. However, for some scholars, palliative care aims to prolong the life of patients.

The acting of the multidisciplinary team towards the child and family during the phase of palliative care in pediatric oncology was highlighted by scholars for success in this model of care. In this sense, were also highlighted the guidelines which were given to the child on conduct and possible complications, in addition to the support for the patient and the family. Spirituality, usually related to palliative care, was not mentioned by any of the participants.

Palliative care in pediatric oncology involves a number of complex issues: the impossibility of cure; the break of life expectancy that is projected for the child; the end of a fragile being that is protected in our culture and family. It is understood that, by its complexity, palliative care in pediatric oncology needs to be addressed during the graduation of health professionals, being this the first step to awareness and preparation of the future professional.

As limitation of research, it is pointed out the scarcity of publications related to palliative care education in pediatric oncology in nursing graduation courses, to expand the discussion and comparison of this study. In this sense, it is suggested that further research address the subject, with respect to both the training of nurses, and in the training of other health professionals.

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