



REVIEW ARTICLE

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PALLIATIVE CARE FOR THE CHILD / ONCOLOGICAL ADOLESCENT: NARRATIVE REVIEW

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ABSTRACT

Objective: To know what is in the national scientific literature on palliative care in pediatric oncology unit. **Methodology:** This is a narrative review, which gathers and summarizes the scientific knowledge produced by analyzing the results already disclosed in published studies. For this, the data were collected from August to October 2015, with the inclusion criteria for selection of articles match the proposed theme, available in full format in English, published from 2007 to 2013. The literature It was conducted by searching the following databases: Latin American and Caribbean Health Sciences (LILACS) and Scientific Electronic Library Online (SciELO). From the following keywords: Palliative Care, Child / Youth, pediatric oncology. **Results:** From the selection were framed five articles, One of four LILACS and SciELO. **Final Thoughts:** Selected articles reinforce the disease changes the daily life of the child, the family and also the nurses, especially when the child's life prognosis is not favorable. Nursing cares not only for life, but also relieves the suffering of patients who no longer have a real chance of cure for their disease, through palliative care.

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INTRODUCTION

The child is a social being, in the world, in the process of growth and development and from the environment where he lives, can influence his formation and his personality. Given this, it is expected that the child's daily life will be full of joys and jokes. However, this reality becomes distant when there are problems related to health, since several diseases affect the world of children, among them cancer. Illness and hospitalization give rise to feelings in the child arising from fear and anxiety about what is happening and what may happen in their daily lives, altering the life routine of many of them. The need for hospitalization makes the child feel abandoned, because it is removed from the family context, having to leave his home, his friends, school, everything that is significant in the family and child world in which he is accustomed and knows. In this context, she feels forced to be in a totally foreign environment to treat the illness she is

suffering, exposed to painful and unpleasant procedures, which she does not understand and is often not explained to her. The hospital environment can cause a psychological and emotional state of the child or lead to losses that remain even after hospital discharge (MITER, 2000). In the hospital environment there is greater attention with the care of the disease, but, often, they forget the psychological satisfaction of the sick person. Therefore, hospitalization may also be considered a disease for the child, who needs to be hospitalized and is doubly ill (RIBEIRO; ALMEIDA; BORBA, 2008). In view of this circumstance, the role of the nurse stands out for 24 hours with the child, since considering that the hospital context favors her to lose her references, being away from home and everything that is common in her day to day. In this case, the child requires greater attention and care, and any disruption interferes with the quality of life and full growth and development (MITER, 2000). Childhood cancer is currently one of the most common diseases affecting children and adolescents, such as leukemias affecting white blood cells, tumors of the central nervous system and lymphomas, uncontrolled multiplication of abnormal cells that can develop

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anywhere of the organism. According to data obtained by the Inca (2014b), in Brazil, cancer is already the leading cause of death (7% of the total) among children and adolescents from 1 to 19 years old, in all regions of the country. It is estimated that about 11,840 new cases of cancer occur in children and adolescents per year in Brazil. In this perspective, hospitals have sought to meet this demand of patients with trained professionals who can perform quality care for their survival. The specialized units to attend children with cancer are classified as oncological units, because in these spaces they study the different types of cancer, trying to understand how they develop in the body. It is the place of action of a multidisciplinary team that involves doctors, nurses, psychologists, nutritionists, physiotherapists, among other professionals. The oncological treatment is always individualized, each patient and pathology have their singularity (BARROS; PONTE, 2013). Given this, it is perceived that it is necessary for professionals to be sensitive to human suffering, being able to take positive responsibility for those who suffer, being willing to dialogue, respecting freedom and recognizing the greatness of the human being in diverse (BOUSSO *et al.*, 2013). Oncology treatment is often aggressive and some children end up not responding to therapy, when all the possibilities of cure are exhausted, receiving a palliative treatment. The World Health Organization (WHO) defines palliative care as integral care to patients, which do not correspond to curative treatment, in order to maintain as a priority, the improvement of the quality of life for the patient and his / her relatives. To this end, care needs to be performed by a multidisciplinary team that seeks relief from symptoms and avoids pain and suffering (BRASIL, 2014a).

Palliative care encompasses death as a natural process, does not extend death or the dying process, provides relief from pain and other symptoms and complements daily care, as well as providing assistance so that patients can live as actively as possible, accompanying the family and caregivers in the process of mourning (BERTACHINI and PESSINI, 2004). In this context, the nurse who is permanently in the care of the child and his / her family needs to pay attention to the importance and the need for palliative care in pediatric oncology unit. It is important to carry out a humanized and quality care that provides both the child and his family security and comfort in the face of the problem they are experiencing. Thus, it will be possible to form a bond between the nurse, the child and the family, making the hospital environment less traumatic, more welcoming and trustworthy between the two. In this sense it is questioned: What is being published in the national scientific literature on palliative care in pediatric oncological units? And as an objective: to know what exists in the national scientific literature on palliative care in pediatric oncological units.

METHODOLOGY

The present study consists of the bibliographical research developed by the method of narrative revision, which gathers and synthesizes the scientific knowledge produced, through the analysis of the results already evidenced in other studies. In order to make it operational, the following steps were used: establishment of the objective, criteria for the selection of the sample, definition of the information to be extracted from the selected articles, analysis of the results, presentation and discussion of results (URSI and GAVAO, 2006).

Data were collected from August to October 2015, and inclusion criteria were defined for selection, which corresponded to the proposed theme, articles available in full format in the Portuguese language and published in the period 2007-2013, excluded works in a foreign language, outside the period determined and that did not correspond to the theme. The bibliographic survey was carried out by means of searches in the following databases: Latin American and Caribbean in Health Sciences (LILACS) and Scientific Electronic Library Online (SciELO), from the following keywords: Palliative Care, Child / Adolescent, Pediatric Oncology. Based on the selection criteria, five articles were included that corresponded to the inclusion criteria, one from LILACS and four from Scielo. The articles were identified with the letter A of article following the numerical order. The analysis of the data occurred through the hierarchical classification of the evidence of the studies (GALVÃO; SAWADA, 2005). Because it was a bibliographical research, it was not necessary the approval of the ethics committee nor the authors' concession, since these are publications available in the electronic medium, in an internet database. In this way, it facilitated the search and diffusion of scientific production by health professionals and students.

RESULTS AND DISCUSSIONS

From the selection, the five framed articles that approached the theme of the study, are characterized as shown in Table 1. As shown in Table 1, A1 aimed to know the nurse's perception of the child with cancer under palliative care and discuss how this perception of the nurse interferes with the care given to the child with cancer. From this study, it was evidenced that the palliative care to the child with cancer causes suffering, because the death will be inevitable and it is a difficult and painful moment. This suffering is permanently experienced by both professionals and family members. In the specific case of nurses, this practitioner often feels failed, because during his academic training the main focus is the discussion on curative treatment and death is not seen as a possibility for care in these cases. The proximity to the patients provokes emotions and feelings, leaving the health professionals vulnerable to the psychic suffering and, consequently, leading to the sickness of these professionals in relation to the work environment (RIOS, 2008). In addition, the continued conviviality with death causes the professional to witness the experience and the experience of suffering that can lead to psychic exhaustion and loss of interest in the work environment (Queiroz, 2008)

A2 aims to know the experiences and perceptions of the nursing team regarding the family of the child in palliative care in the pediatric oncology of the Hospital of Clinics of Porto Alegre (HCPA). The study highlights the changes involved in caring beyond cure, as the process of dying has changed a lot in the last few years, as most of the time the patient dies at home accompanied by his relatives. Currently there is the "hospitalization of dying", in which patients end up being assisted by the health team in its finitude, the nursing team becomes responsible for performing the care, strengthening the bond of this with the team generating an explosion of feelings, both for their families and for the professionals at the moment when the child finds himself in his finitude. In this study the results showed that it is important to take advantage of the moment lived, since the now is unique and with this thinking propitiates and encourages the family to remain in the most active way in promoting a humanized care to their child.

Table 1. Selected articles in SCIELO and LILACS databases

Identification	Title	Goal	Author (s)	Newspaper Published	Year of publication
A1	Palliative care to the oncological child in the situation of living / dying: The optics of nursing care	Knowing the perception of the nurse before the child with cancer under palliative care; and discuss how this perception of nurses interferes with care of children with cancer under palliative care.	Barbara Soares Avanci Fabiano Mizael Carolindo Nina Paula Cruz Netto Fernanda Garcia Bezerra Góes	Esc Anna Nery Nursing Magazine 2009 out-dez; 13 (4): 708-16	2009
A2	The family of the oncological child in palliative care: the look of the nursing team	To know the experiences and perceptions of the nursing team in relation to the family of the child in palliative care Pediatric Oncology, hospital of clinics of Porto Alegre (HCPA)	Silva, Adriana Ferreira da; Issi, Helena Becker; Motta, Maria da Graça Corso da.	Science, Careand Health	2011
A3	Experience in palliative care leukemia: the vision of professionals	Understanding the vision of multidisciplinary team before the child leukemia in palliative care.	Danielle Moreira Nascimento Thaisa Gino Rodrigues Mayara Rosário Soares Marina Lira Santos Rosa Selma Maria da Fonseca Viegas Patrícia de Oliveira Salgado	Science and Collective Health, 18 (9): 2721-2728, 2013	2013
A4	Importance of communication in palliative care in pediatric oncology: focus on Humanistic Nursing Theory	To investigate and analyze communication in palliative care in pediatric oncology, from the point of view of nurses, based on the Humanistic Theory of Nursing.	Jael Rúbia Figueiredo de Sá França, Solange Fátima Geraldo da Costa, Maria Emilia Limeira Lopes, Maria Miriam Lima da Nóbrega, Inacia Sátiro Xavier de França	Rev. Latino-Am. Nursing vol.21 no.3 Ribeirão Preto June 2013	2007
A5	Nursing in palliative care for children and adolescents with cancer: an integrative review of the literature.	To identify nursing actions in palliative care for children and adolescents with cancer, considering the specificities of the disease and the death process.	Thailly Faria da Costa; Maria Filomena CeolimII	Nursing Journal of the State of Rio Grande do Sul	2010

In order to understand palliative care, the health professional needs to pay attention to the needs of individual care and thus to consider the four basic human needs: exist, think, feel and act in the world. Care is the indispensable of the respect and value of human dignity and it is through a dignified care that the professionals show support for the patient and his relatives. Therefore, in this critical phase of end-of-life, the entire therapeutic set should be based on this action (ALVES et al., 2013). More broadly, it is of the utmost importance that the nursing team is permanently mindful of providing care also to family members who visit their loved one in the oncology unit, although they often end up falling ill together. This fact is explained by the fact that biopsychosocial and spiritual destabilization occurs, mainly evidenced by some degree of anxiety, mainly caused by the risk of loss, lack of knowledge of what is happening and by a long waiting period (Chaves, Silva, Souza, 2006). A3 aimed to understand the vision of the multidisciplinary team before the child with leukemia in palliative care. It was observed in the present article that the professional who works in the oncology unit provides a humanized care to the child with leukemia in palliative care, offering maximum comfort and pain relief. The speeches of the professionals interviewed in this study evidenced the difficulty in dealing with the feelings, emphasizing that they feel unable to act in the face of death.

In order to do this, the nursing team in charge of pediatric cancer patients and their families needs, in addition to the preparation of the intervention plan, the application of technical-scientific knowledge and the execution of activities with the interdisciplinary team, to be emotionally prepared to serve this clientele. In this way, it can take into account the importance of maintaining a care that involves the patient's bio-psycho-social context, in relation to what is an integral being, impregnated with different feelings (BATISTA et al., 2011).

The purpose of the A4 was to investigate and analyze communication in palliative care in pediatric oncology, from the point of view of nurses, based on the Humanistic Nursing Theory. This article evidenced the importance of the human relationship, showing that communication with the child in the termination process is essential for interpersonal contact, seeking to provide better care and quality care. In the interviewees' statements, it was evidenced that the health professional working with the terminally ill child needs to be attentive to verbal and non-verbal communication, since often the child does not communicate with words, but with the eyes, with a smile or, even with gestures, so we need to understand what that child is feeling, always trying to pass the maximum of trust to the patient and his family. Appropriate communication is an important method for comprehensive and humanized care, because through it it is possible to recognize the needs of the patient as well as their family members. When the nurse has this method in a verbal and non-verbal way, thus allowing the patient to participate in the decisions and specific care related to their pathology, in order to achieve a dignified treatment (ANDRADE; COSTA; LOPES, 2013).

The A5 aims to identify, in the literature, nursing actions in palliative care to children and adolescents with cancer, considering the specificities of the disease and the death process. The article reinforces that nursing care at the terminal should be driven by actions that meet the biopsychosocial needs of the child / adolescent and his / her family taking into account the different demands that may arise at that moment. The imminence of the child's death brings suffering and pain to the family and friends, because it is very difficult to accept the death of the child / adolescent seen as being full of vitality. This study made it possible to observe the relevance of palliative care in pediatric oncology practice, emphasizing the need to maintain the dignity and quality of life of the terminally ill child. Palliative care, according to Bertachini and

Pessini (2004), is a patient's right and an assignment of health professionals, because the more preventive the interventions become, the more effective they will be, bringing the expected result and the search for meaning. own life. It is very important to allow the child to be active in the process of becoming ill, as well as being able to have family support and the team's ability to be instructed to make their own decisions. In order to do so, nurses have a primary role in helping the child and family in the context of illness and hospitalization, showing a sense of security and solicitude in the care taken, soothing the suffering of both.

Final Considerations

The selected articles reinforce that a problem alters the daily life of the child, the family and also the nursing professionals, especially when the child's life prognosis is not favorable. Nursing is not care for life, but also for patients who no longer have a chance of cure for their illness through palliative care. In this sense, it is believed that its professionals must attend to the issues that permeate the context of the end of life in order to improve their care in a systemic and human way, from the patient's home to the hospital environment. In the area of pediatric oncology it is fundamental that the nursing team has the capacity to maintain good communication and relationship with the child and with his family. However, professionals working in the area, through the relationship they develop and the trust they achieve, are emotionally involved and end up suffering when the child moves from a curative to a palliative care, and this suffering is more intense when the child experiences the process of the end of life. It is a right of the patient to have a dignified death without suffering. In this way the dedication of the professionals involved in palliative care should be employed in order to alleviate pain, promote maximum comfort and well-being in this final phase of life, providing individualized assistance, since each patient has different values and beliefs.

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