PALLIATIVE CARE IN CHILDREN WITH CANCER: INTEGRATIVE REVIEW

CUIDADOS PALLIATIVOS EN NIÑOS CON CÁNCER: REVISIÓN INTEGRADORA

Andreyna Javorski Rodrigues¹, Magaly Bushatsky², Waleska Delgado Viaro³

RESUMO
Objetivo: analisar a produção de conhecimento acerca dos cuidados paliativos em crianças com câncer publicadas por enfermeiros. Método: revisão integrativa com vistas a responder à questão de pesquisa << Quais são as contribuições produzidas por enfermeiros para os cuidados paliativos em crianças com câncer?>>. As bases consultadas foram LILACS, CINAHL, Scopus e biblioteca virtual Scielo de janeiro de 2004 a 2014. Resultados: a percepção do cuidado à criança e a família foi o tema mais abordado, ficou evidente que o cuidar da criança com câncer sob cuidados paliativos gera sofrimento e uma variedade de emoções para o profissional. Dentre as ações de enfermagem foi possível destacar o manejo da dor, o apoio à família, os cuidados com o corpo e a comunicação como estratégias fundamentais para a assistência. Conclusão: recomendam-se estudos de intervenção educativa com equipes, que trabalhem com oncologia pediátrica, bem como contemplar esta temática durante a formação do profissional de saúde. Descritores: Enfermagem Oncológica; Cuidados Paliativos; Enfermagem Pediátrica.

ABSTRACT
Objective: analyzing the production of knowledge about palliative care for children with cancer published by nurses. Method: an integrative review in order to answer the research question << What are the contributions made by nurses about palliative care for children with cancer?>>. The bases consulted were LILACS, CINAHL, Scopus and Scielo virtual library, from January 2004 to 2014. Results: the perception of care for children and the family was the most discussed topic; it became clear that care for children with cancer under palliative care generates suffering and a variety of emotions for the professional. Among the nursing actions it was possible to highlight pain management, support family, body care and communication as key strategies for assistance. Conclusion: there are recommended studies of educational intervention with teams working with pediatric oncology and include this issue in the training of health professionals. Descriptors: Oncology Nursing; Palliative Care; Pediatric Nursing.

RESUMEN
Objetivo: analizar la producción de conocimiento publicada por enfermeras acerca de los cuidados paliativos para niños con cáncer. Método: una revisión integradora con el fin de responder a la pregunta de investigación << ¿Cuáles son las contribuciones hechas por las enfermeras acerca de los cuidados paliativos para niños con cáncer?>>. Las bases consultadas fueron LILACS, CINAHL, Scopus y Scielo biblioteca virtual, desde enero de 2004 a 2014. Resultados: la percepción de la atención para los niños y la familia fue el tema más discutido, se hizo evidente que el cuidado a los niños con cáncer sob cuidados paliativos genera sufrimiento y una variedad de emociones para el profesional. Entre las acciones de enfermería fue posible destacar el manejo del dolor, el apoyo a la familia, el cuidado del cuerpo y la comunicación como estrategias clave para la asistencia. Conclusión: se recomiendan estudios de intervención educativa con los equipos que trabajan con la oncología pediátrica e incluir este tema en la formación de los profesionales de la salud. Descriptores: Enfermería Oncológica; Cuidados Paliativos; Enfermería Pediátrica.

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INTRODUCTION

According to estimates from the National Cancer Institute, for the biennium 2014/2015 there are expected around 576.00 new cases of cancer in Brazil, being the estimate in children and adolescents up to 19 years old of 11.840 new cases. Although pediatric cancer represents only 3% of the total of all tumors presented by the population, the disease is the second leading cause of death in this age group, exceeded only by the external cause deaths.¹

Children’s cancer is considered a public health problem as it still carries a high infant mortality rate, high costs related to the detection, diagnosis and treatment, as well as financial loss because of human labor reduction potential.²

Even though it was considered a fatal disease until two decades ago, with the advancement in technology and health care, pediatric cancer is now a treatable and with the potential to cure disease, which increased the survival rate. However, even with these advances, approximately 25% of cases cannot respond to antineoplastic therapy. Thus, many children and their families will require palliative treatment, and that unknown to many professionals working in the area.³

The World Health Organization (WHO) in 1990 conceptualized and redefined in 2002, Palliative Care (PC) as the active total care of patients whose disease is no longer responsive to curative treatment. The concept of palliative care had its origin in the hospice movement, created by the medical/nurse Cicely Saunders, who described and defended the philosophy of care for the person who is dying, in order to relieve the physical, psychological, social and spiritual suffering, whose essence focuses on the act of caring.⁴

The specialty of pediatric oncology causes pain, suffering, anxiety and stress, and the touch with death generates a feeling of powerlessness in nursing, mainly due to the bond that builds professional with the children and their families, especially when it comes to children critically ill.⁵

A research conducted in a pediatric department of a public hospital with reference in Hematology in the state of Rio de Janeiro, found that despite the nurses share feelings and emotions during the process of death/dying child in PC, the assistance provided to them and the family is held in the same way, regardless of their situation or condition.⁶ The literature has shown that many children with end-stage are admitted to Pediatric Intensive Care Units, which end up getting centralized treatment in healing, excluding the PC and real needs in the final moments of life.⁷

It is considered appropriate to carry out a detailed study about child care in the terminal phase. Using the method proposed by review of studies, in particular the integrative review, it may provide to the nursing staff who works in this area, particularities of palliative philosophy, more specialized care and integral to patients and family throughout the process death and mourning.

Despite advances in therapy and approach to pediatric oncology, in Brazil there are few nursing works focusing on PC; this position it is necessary to investigate and systematize the knowledge produced by nurses about nursing care in PC in children with cancer.

OBJECTIVE

- Analyzing the production of knowledge about palliative care for children with cancer published by nurses.

METHOD

Article from the monograph "Palliative Care for Children with Cancer: An integrative review" submitted to the Residency Program in Nursing Oncology, University of Pernambuco/UPE, 2014.

This is an integrative review study (RI) which allows the inclusion of studies with different methodological approaches (quantitative and qualitative).⁸

The methodological procedures considered essential for the construction of RI are: question formulation and review objectives; establishment of criteria for selection of articles; categorization of studies; assessment of studies included in the RI; data analysis and presentation of results.⁹

Respecting the referred criteria it was drawn up the following guiding research question: what are the contributions made by nurses about palliative care for children with cancer?

The pursuit of these contributions has been accessed in the following databases: Latin American and Caribbean Literature in Health Sciences (LILACS), Cumulative Index to Nursing and Allied Health Literature (CINAHL), Scopus and virtual library SciELO (Scientific Electronic Library On line).

The descriptors for the search in the databases were set from the query in the Health Sciences Descriptors (DeCS) and the Medical Subject Heading (MeSH), which is characterized in a controlled vocabulary
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The controlled descriptors selected in Portuguese, English and Spanish to answer the research question were: Palliative Care; Hospice Care; Palliative Care; Oncology Nursing; Oncology Nursing; Nursing Oncology; Child; Child; Child.

It is important highlighting the use of the Boolean operator AND in the descriptors in English, Portuguese and Spanish to the search refinement of articles in the databases chosen for collection.

The study included articles published in Portuguese, Spanish and English; studies with a qualitative and quantitative approach, those who had at least one nurse in the context of authors and articles published from January 2004 to January 2014 were excluded editorials, review studies, summaries and experience reports.

The collection of relevant information for the review was accessed through an instrument already validated of Usi authored adapted to the addressed study, containing the following topics: identity, headquarters institution of study, type of journal, methodological characteristics of the study, main results and conclusions of publication.

The methodological analysis of research using the qualitative method was guided by the criteria of the protocol Critical Appraisal Skills Program (CASP)\(^\text{11}\). To categorize the same was chosen for scoring the items in: yes - 1 point; and partly not - zero points. Thus ranked as Category A studies with higher scores than or equal to nine, category B with scores between seven and eight, and studies with lower scores on the seven were included in category C. Therefore, were part of this study categorized research in the and B. the levels of evidence from research that adopted the quantitative method defined by the Oxford Centre protocol of Evidence-Based Medicine.\(^\text{12}\)

RESULTS

The initial search made to databases resulted in 33 articles accessed with the use of controlled descriptors; from these, nine were included for analysis. The details of the deletion are shown in Figure 1.

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**Figure 1.** Description of publications accessed and selected for the study. Recife/PE. 2014.
The result of the analysis of the publications selected for this review is presented in three figures.

<table>
<thead>
<tr>
<th>Number/Authors/Year</th>
<th>Title of the articles</th>
<th>Country</th>
</tr>
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<tbody>
<tr>
<td>1. Graves, S; Aranda, S 2005</td>
<td>When a child cannot be cured: reflections of health professionals.</td>
<td>Australia</td>
</tr>
<tr>
<td>2. Silva, A. F.; Issi, H. B.; Motta, M. G. C. 2006</td>
<td>Palliative care: the look of the nursery team</td>
<td>Brazil</td>
</tr>
<tr>
<td>4. Mutti, C. F.; Padoin, S. M.; Paula, C. C. 2012</td>
<td>Spatiality of be-professional-of- nursing in the world of care to a child who has cancer</td>
<td>Brazil</td>
</tr>
<tr>
<td>5. Monteiro, A. C.; Rodrigues, B. M.; Pacheco, S.T.A. 2012</td>
<td>The nurse and the care for the child with cancer without possibility of current cure</td>
<td>Brazil</td>
</tr>
<tr>
<td>6. Souza, L. F., et al. 2013</td>
<td>Death worthy of a child: perception of nurses from an Oncology Unit</td>
<td>Brazil</td>
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</tbody>
</table>

From the selected articles, 55.5% of the publications were in LILACS and 44.4% in SCOPUS, there were not selected articles in Scielo and CINAHL bases after the adoption of the inclusion and exclusion criteria. An article was published in 2005 representing 11.1% of the sample in 2006 found two publications (22.2%) in the years 2007 and 2009 was published only one article each year (11.1%); in 2010 were accessed two articles (22.2%), three (33.3%) in 2012 and only one article (11.1%) was accessed through the month of January of the year 2014.

Among the places where they were carried out studies, Brazil has the largest number of publications with six articles (55.5%), followed by Australia, with two articles (22.2%), and finally the United Kingdom and the United States with an article (11.1%) published in each country. It is noteworthy that the number of relevant publications in Brazil concentrated in the south and southeastern regions of the country.
Referring to the drawings of the studies, seven (77.7%) had the approach of the qualitative method, and only two (22.2%) used the quantitative method.

Regarding the subject of the research, the majority of the sample (54.5%) was made up of health professionals, 18.2% were parents/caregivers of children with cancer in palliative care and only one study (9%) used children as subjects of study.
With regard to the objectives of the studies, it is observed that most researchers bothered to describe or understand the experiences and perceptions and meanings of health professionals about PC (Studies 1, 2, 3, 4). Few studies have investigated the actions involved in nursing care provided to children and their families (studies 5, 6); international studies (studies 7, 8 and 9) extend the knowledge about PC, bringing in perspective new models of care for that area.

**DISCUSSION**

The majority of studies was a qualitative approach, however the methodological rigor of only two of these were classified in category A. Possibly, the ethical issues involved in the issue in question hamper the research with a quantitative approach, since they were accessed only two articles with this methodology. Adding to this, none of them got evidence levels considered more robust. The results enabled the construction of four themes for the purpose of discussion of the findings: Feelings of the professionals in the child care in palliative care; Bond formation with the child and family; Approach and actions of health professionals in palliative care; new perspectives in palliative care.

<table>
<thead>
<tr>
<th>Studies</th>
<th>Objectives</th>
<th>Main Results</th>
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<tbody>
<tr>
<td>Study 1</td>
<td>Explore critically aspects involved in the transition to palliative care in children with cancer.</td>
<td>Topics like hope, uncertainty and the interface between the cure and palliation were uniquely identified; The time of recidivate was cited as the most difficult during treatment; Professional experience interferes with the care given to the child/family.</td>
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<tr>
<td>Study 2</td>
<td>Learn about the experiences and perceptions of nursing staff in relation to the family of the child with PC in a sector of Children.</td>
<td>The importance of the link between the nurse and the family; Relief from stressful symptoms of physical, mental and spiritual order; Continuing education to caregivers for child care at home; Feelings of failure and sadness that permeate the Act of care carried out by nurse.</td>
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<tr>
<td>Study 3</td>
<td>The perception of the nurse on the children with cancer, and how this perception interferes in the care provided to children with cancer under PC. Understand the meaning for the nursing staff about the care of children who have cancer advanced disease that no longer responds to curative treatments.</td>
<td>Development of links between the nurse and the child/family; Promotion of comfort the child with management of pain and other symptoms; Unpreparedness before the nurse's emotional assistance in children under PC.</td>
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<tr>
<td>Study 4</td>
<td>Analyzing the care of nurse the child hospitalized with cancer disease out of possibility of current cure.</td>
<td>Need of separation between professional and personal life, and psychological preparation of nurses; The professional approach and departure movements develops between the personal and professional life.</td>
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<td>Study 5</td>
<td>Identify the meaning and the interventions of nurses working in pediatric Oncology in promoting dignified death of child.</td>
<td>Focus on actions aimed at the relief of suffering and pain through individualized care; Difficulty of assessing the dimension of pain in children; Confrontation with the sense of finiteness triggered by the child's death.</td>
</tr>
<tr>
<td>Study 6</td>
<td>Describe the types of calls made to a telephone service available to children in PC.</td>
<td>Caregivers of children with solid tumors called more often, primarily for help in pain management and psychosocial support; The need for skills of nurses in providing this service to the competent management of the physical symptoms, psychological and emotional.</td>
</tr>
<tr>
<td>Study 7</td>
<td>Describe the effectiveness of a PC model to promote the death of household children with cancer outside of healing possibilities.</td>
<td>Most of the children died at home, receiving the support of nurses in home care; At the end of life the number of children receiving complementary therapies (massage, psychotherapy, etc.) has increased; During the process of completion of the doctors and social workers have become less involved, being careful to sovereign nursing right now.</td>
</tr>
<tr>
<td>Study 8</td>
<td>Check out the opinions of parents regarding the decision between the PC model with chemotherapy or palliative care support unique, and how health professionals assist in decision-making.</td>
<td>The parents mentioned the importance of maintaining the quality of life, financial health, marital well-being, the family dynamics and the necessary support of health professionals in the decision-making process in choosing care.</td>
</tr>
<tr>
<td>Study 9</td>
<td>Describe the effectiveness of a PC model to promote the death of household children with cancer outside of healing possibilities.</td>
<td>The results enabled the construction of four themes for the purpose of discussion of the findings: Feelings of the professionals in the child care in palliative care; Bond formation with the child and family; Approach and actions of health professionals in palliative care; new perspectives in palliative care.</td>
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Figure 3. Distribution of publications included in integrative review, in accordance with the objective and key results. Recife, PE, 2014.
The feelings of professionals of children under palliative care

During the care provided to the terminal child the nurse is confronted with feelings, sometimes contradictory, that permeate their professional routine which can influence the care provided to patients and family. In study 2, conducted with nursing professionals, there are referred to different feelings, often conflicting ranging from sadness, helplessness and weakness, to overcome the own anxieties and dilemmas that arise in the care of everyday life, not leaving shake or weaken - is to provide ongoing support to the family. The nursing practice in PC is interspersed by a sense of compassion for others, and active communication with the child and family. The implementation of assistance in Palliative Care is confronted all the time with the emotional, psychological and spiritual aspects of professionals who practice, in particular those working in nursing, as these professionals are on duty throughout the period at the bedside of the patient, being confronted with the demand of competitors and recurrent symptoms during their hospitalization.

The process of illness and death is described by nursing professionals in Study 3 as a moment of intense suffering and negativity, which are influenced by feelings of compassion for the child and family, and the professional failure. Since when dealing with patients without therapeutic possibility professional is forced to deal with their own finitude and limitations towards life.

The impact of the death of a child in life was identified by nurses and doctors who provide this care, as they participate actively in the disease process and share the grief with the families. It is important to recognize these professionals understanding about death, as well as, the meaning in their lives, in addition to their own needs.

There are cases where the patient’s suffering is such that, several times, death becomes signified by professionals as pain relief both the patient and the family as the team itself to assist it. Therefore, understand death as the pain of the solution, is a way that professionals are to protect the psychological suffering resulting from loss of patient.

Autonomy in child care is explored in Study 6 as one of the causes of impotence feeling in the pros. At times this professional feel deprived of freedom for decision making in situations involving the child's death. There is an obvious concern with the legal and bioethical issues related to end of life that cause conflicts to the individual exercising care.

Palliative care aims to promote humanization in the final moment of life, through an approach that provides the die with dignity, guided by the ethical principles of respect for human life, such as the principles of autonomy, futility, euthanasia, beneficence, non-maleficence and justice. However, many professionals are unaware of these principles and, in most cases not know how to carry forward the demands of children and families in their care.

Study 1 reports the feeling of uncertainty as a major influencing factor in palliative care of the child. The experiences of the health team in which patients with poor prognosis, but unexpectedly survived, influence the treatment being provided to that patient. To provide care and observe these children, a feeling of uncertainty is generated and the decision to stop treatment and shift the focus of care is less clear and harder.

It is recommended that palliative care in pediatrics are implemented progressively, starting at diagnosis the impossibility of positive response to therapy for healing. Such care, tailored to the needs imposed by the disease and its treatment (evolution, complications, limitations), enable individualized attention that child. That is, the curative and palliative care must coexist in the treatment plan of the patient, and depending on the degree of the disease one becomes more important than the other. It is understood that this proposal minimizes the ethical conflicts of the professionals in the problems experienced by children and their families.

The spatiality emerges as professional protection instrument in the midst of this reality. Study 4 discusses the behaviors of distance and approach the child/family made by the nursing staff in an attempt to separate the professional staff of life. The authors also point out the need for psychological support for professionals in order to prepare them emotionally in child care/family terminally.

The difficulty of health professionals in dealing with this event could be mitigated by creating spaces of reflection in services. These spaces would be times when professionals could express their anxieties, conflicts and mixed feelings, for in the day-to-day just discussing the issues related to death.
The studies included in it reveal the fragility of those who care, or who provides care for children and families faced with the terminally ill of life. The authors emphasize the importance of assistance and psychological distress of those who are ahead of PC, because the health care team would also need to be looked after.

♦ Formation of bond with the child and the family

The bond formed between the professional and the child/family is seen as an attachment relationship, conceived as any form of behavior that a person reaches and maintains the proximity to a different and preferred individual. For the child, the person who comes to maternal, keeping a good social interaction and responding to their signals and needs, it is the attachment figure. 21

The importance of the formation of bonds and emotional involvement are emphasized in Study 6. The authors of this study point out that the establishment of the link enables greater trust between child, family and nurse. Consequently, the professional realizes that, in this way, treatment and care provided to the child and family become more effective and less painful. 27

The family hopes of palliative care programs professional skills, confidence in the team members and the safety of care. Often, satisfaction with the activities of health professionals are considered high in the dimensions of professionalism, professional skills, confidence and friendship. 22

In Study 5 the authors identified that the care in pediatric CP is reflected in the concern for the other, still found that professionals provide care and affection ties, and for the care actions demonstrate manifestations of support and understanding for the child and his family, strengthening ties. 23

In palliative approach to care involves human acts in the process of assisting the patient with cancer and their families. The art of care is based on the source of life, entangled in a mutual exchange of feelings and experiences, which enlivens, the beings involved, trust, empathy and respect that spring from being with another authentically. 24

The recurrent hospitalizations are pointed in Study 2 as a crucial situation that promotes the creation and strengthening the bond. Due to the change of environment children and families end up building a significant identification with health professionals, especially nurses, forming an important link to the caregiver while they are providing their care. 13 In addition, the study reports that 3 bond arises from exchange and sharing of emotions and feelings through the act of listening, dialogue, allowing the child to acquire confidence in who cares, and that the family share their experiences, fears and feelings about the situation of its being in the process death. 6

The family reported the key role of human relations during this period. These indicate that the interpersonal relationship based on empathy and compassion would be the main benefit they expect from those who care for them. The human relationship seemed to be the essence of care that would sustain the faith and hope in difficult times. 25

In Study 9 parents reported the importance of the bond and trust in the health team in the decision-making moment between a model of palliative care with the use of palliative chemotherapy or with only supportive care. These stated that during the disease process they seek to support the professionals in order to promote the welfare and comfort of the child. 26

In providing palliative care, the nurse realizes his participation by supporting the patient and family to face the terminal phase. Such participation involves not only managing the pain, respiratory failure, anxiety and depression, but the share with the patient and family in the decisions of care. 5

This theme revealed the uniqueness and the essence of forming a connection to the professional who intends to work with PC. All studies show that the family feels supported and stronger to keep walking and taking decisions regarding the care of a child, considered by staff and outside therapeutic possibilities, when trust in professionals to attend.

♦ Approach and actions of the professionals on palliative care

The role of nursing staff is paramount and essential to providing maximum comfort to the patient, helping them in the process of dying with dignity, to use the best possible way, the time remaining. 25

These professionals need to present an effective palliative care plan in order to preserve the child’s quality of life, offer time and information for the process of decision-making as well, able to communicate in the planning of care required by the child and family and thus generate tranquility and a sense of control in difficult times. 27

Study 1 alert to the fact that children with cancer often receive aggressive therapeutic
and experience great suffering in the last month of life, which could be reduced through the PC. The authors consider that the continuity of aggressive treatment leaves little time for the implementation of nursing actions consistent with the palliative philosophy. Thus, a team, well prepared, should discuss when to stop curative treatment and start the PC, and consequently the suffering of children and their families could be minimized.18

The terminal patient in the design of medicine is rated as one out of therapeutic possibilities of cure, when interventions can reverse its board ran out and his life is maintained often thanks to technology. Thus, most of the health professionals who work with terminally ill patients face challenges in trying to promote a high quality service, not to mention the side of the humanized care.20

Among the various symptoms that affect children in the latter stages of life, pain in Study 2 is cited as a major cause of suffering. The patient's pain in CP is not restricted to physical pain due to disease progression, but it is also a reflection of the situation experienced by the patient.13

The concept of “total pain” was first introduced by Cicely Saunders. Patients should be treated as people, not as diseases, and be seen holistically, including the physical, emotional, social and spiritual aspects. Ignoring any of these dimensions becomes incomplete patient approach, since these aspects influence the perception and intensity of pain experienced by the individual. That is, the “total pain” referred to the authors can be understood as an endless pain that starts in the physical body and lasts for the soul.28

In Study 5 nurses emphasize that pain control is considered a basic principle for the quality of life, but in children the treatment of pain is quite critical, because of the difficulty of assessing the extent of pain in this age group.23

Pain relief is currently seen as a basic human right and therefore it is not only a clinical question, but also an ethical situation that involves all health professionals. Thus, the adequate preparation of nurses is a key strategy for the control of pain and prevalent symptoms in cancer patients in CP, as it is these professionals who most often evaluate the effectiveness of the implemented support measures.29

It is impossible to promote a dignified death in a child if it is with physical and/or emotional distress; therefore nurses investigated by Study 6 reported taking actions in order to reduce the suffering through measures that relieve pain and provide comfort to the child. Such assistance is focused on the principles of holistic care, teamwork and communication with family members.17

The last case, as referred to in Study 2, and also addressed in Study 3, characterized by the final care of the body done after the death of the child, and this follows the established routine, usually according to family culture and/or society.6,13

Care of the body is presented as a strategy to extend patient care. The nursing professional is the best person for this care due to therapeutic patient-provider relationship established with him prior to the occurrence of death, making them more sensitive to the act, preparing them with dignity and care for the last sensibility. This child must be translated into genuine attention to the family and symbolizes the close, with dignity and compassion, of palliative care provided by the nursing team.16

The complexity of care to children under PC proved throughout the construction of this theme. The studies analyzed indicate the commitment of nursing professionals to reduce the suffering of children in order to promote a humanized care and dignified death. Worth to point out that the analyzed studies include a different view of the team for the family, as even after the death of the child, that still need care.

♦ New perspectives about palliative care

From the twentieth century, the power of the medical intervention has grown too, without a concomitant focus on the impact of this new reality in the quality of life of the sick. Cultural aspects associated to social factors, such as the difficulty of treatment of a terminal patient at home, led to institutionalized death.20

The Intensive Care Units (ICUs) associated with the advancement of medical technology have grown substantially. In the hospital environment, sophisticated technology directs the staff of intensive care to put aside the concept of death and its meaning in favor of specialized treatment.31

On the one hand, this reality expands the therapeutic perspectives in different clinical situations, but on the other, cause receivership possibility of prolonging life at all costs, which often implies futile treatments. Today, about 70% of deaths of patients under PC in Brazil occur in highly complex treatment services32.
The National Academy of Palliative Care alerts to the fact that there are few palliative care services in Brazil. Still lower is the number of those who provide care based on scientific criteria and quality.\(^3\)

The difficulty in addressing new CP models in the country has its reflection in the literature is still scarce. Only two studies, both international, brought information about the new arrangements in the care of children with no prospect of cure cancer.

In Study 7 we evaluated the type of telephone calls made to a phone service support to caregivers of children in PC cancer. The service worked during the times where it became more difficult access to specialized care (from 17:00 to 08:00 on weekdays, and 17:00 on Saturday until 08:00 on Monday during the weekends). The links were sent to nurses with extensive experience in pediatric oncology palliative care and who had knowledge of the clinical history of the child.\(^4\)

It was observed in this study that caregivers that most used phone service were those who took care of children with solid tumors, and that most of the links were to receive some sort of psychosocial support, or to receive instructions in the management of symptoms, especially the pain.

Study 8 describes the type of palliative care provided to children with cancer, and death places this population. The authors note that about 77% of the patients died at home, making clear the preference of the family and the importance of choosing the place of care and death.\(^5\)

While on the study, the authors describe the palliative care was provided by a multidisciplinary team, and that at the beginning of palliative care, oncology nurses and oncologists were seen equally in relation to the supportive care offered. However, in the last month of the child’s life, parents realized that oncologists have become less involved in the care, while the oncology nurses exercised predominant form of assistance to children and their families.

Possibly the families' perception in relation to the greater involvement of nurses in the final child care is the fact that nursing has an essential role in the team's performance, since the PC are inherent to their practice as in their daily lives, this professional incorporates the science and the art of care, aiming to support and comfort in the different stages of life in terminally and also during the mourning period.\(^6\)

In this theme we observe that even countries that already offer PC to children without therapeutic possibility, new proposals for this type of assistance are still incipient. Despite the complexity of this subject research needs to test new models of care in PC, especially in Brazil where the literature on this subject is scarce.

**FINAL REMARKS**

From the analysis and discussion of the articles selected for this study it was clear that the care of children with cancer in palliative care generates suffering and a variety of emotions for professional, among them the ethical issues surrounding the care at the end of life. Regarding the nursing actions were identified pain management, support family, body care and communication as fundamental strategies for palliative care. Health professionals also reported lack of preparation to provide such a unique service that goes beyond the technical aspects.

The methodological design of most studies, and the results presented suggest that research on palliative care is still poor, and the knowledge produced by them has little involvement in the practice of PC.

It is believed that one must go beyond the descriptive exploratory studies; prospective or retrospective cohort designs could reveal aspects or factors that improve the quality of care for children without cancer therapeutic possibility.

Furthermore, it is essential that the approach of palliative care be present in the curriculum, allowing at least the theoretical contact with the theme during the training of health professionals.

**REFERENCES**


Palliative care in children with cancer...


