# Assistance to children in palliative care in the Brazilian scientific literature

## *Assistência à criança em cuidados paliativos na produção científica brasileira*

## *Asistencia al niño en cuidados paliativos en la producción científica brasileña*

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## ABSTRACT

**Objective:** To describe what has been published in Brazilian scientific literature regarding pediatric palliative care.

**Data sources:** Bibliographic review with a descriptive approach. In LILACS and SciELO databases, the descriptors "palliative care", "child", "pediatrics", "terminal illness" and "death" were sought, from January 2002 to December 2011. The eight selected articles were analyzed according to year of publication, type of study, data collected, target population, pathology, professionals involved, types of care and main findings.

**Data synthesis:** Regarding the year of publication, there was an increase in the number of publications related to pediatric palliative care. Regarding the type of study, four articles were literature reviews and four were qualitative researches. Data was collected mainly by semi-structured interviews. The participants of the majority of the studies were children's relatives and health professionals. The main pathology addressed was cancer and the nurses were the most frequently cited professionals. The types of care provided were related to physical aspects, general care and psychological, social and spiritual aspects (less emphasis). The main findings were: little emphasis on the children's needs, the importance of including the family in the care provided and the lack of preparation of the health team.

**Conclusions:** Despite the difficulties and the challenges in establishing pediatric palliative care, many articles brought important considerations for the development of this practice in the country.

**Key-words**: child care; palliative care; Brazil.

## RESUMO

**Objetivo:** Descrever o que tem sido publicado na produção científica brasileira quanto à assistência à criança em cuidados paliativos.

**Fontes de dados:** Estudo de revisão bibliográfica com abordagem descritiva. Nas bases de dados LILACS e SciELO, buscaram-se os descritores "cuidados paliativos", "criança", "pediatria", "terminalidade" e "morte", selecionando-se artigos de janeiro de 2002 a dezembro de 2011. Os oito artigos selecionados foram analisados conforme o ano de publicação, o tipo de estudo, a forma de coleta de dados, o público-alvo, a patologia, os profissionais envolvidos no cuidado, os tipos de cuidado oferecido e os principais resultados.

**Síntese dos dados:** Quanto ao ano de publicação, percebeu-se aumento no número de publicações referentes à área dos cuidados paliativos pediátricos. Quanto ao tipo de estudo, quatro artigos eram de revisão bibliográfica e quatro eram pesquisas qualitativas. A principal forma de coleta de dados foi a entrevista semiestruturada. Os participantes da maioria das pesquisas foram os familiares da criança e os profissionais da saúde. A principal patologia abordada foi o câncer e os enfermeiros foram os profissionais mais citados. Os tipos de cuidado oferecido relacionaram-se aos aspectos físicos, aos cuidados gerais e aos aspectos psicológicos, sociais e espirituais (menor ênfase). Os principais resultados encontrados foram: pouca ênfase nas necessidades das crianças, importância de incluir os familiares no cuidado prestado e falta de preparo da equipe de saúde.

**Conclusões:** Mesmo sendo relatadas dificuldades e desafios para o estabelecimento dos cuidados paliativos pediátri-

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cos, muitos artigos apontaram reflexões importantes para o desenvolvimento da prática no país.

**Palavras-chave**: cuidado da criança; cuidados paliativos; Brasil.

## RESUMEN

**Objetivo:** Describir lo que se viene publicando en la producción científica brasileña respecto a la asistencia al niño en cuidados paliativos.

**Fuentes de datos:** Estudio de revisión bibliográfica con acercamiento descriptivo. En las bases de datos LILACS y SciELO se buscaron los descriptores «cuidados paliativos», «niño», «pediatría», «terminalidad» y «muerte», seleccionándose artículos de enero de 2002 a diciembre de 2011. Los ocho artículos seleccionados fueron analizados conforme al año de publicación, el tipo de estudio, la forma de recolección de datos, el público meta, la patología, los profesionales implicados en el cuidado, los tipos de cuidado ofrecido y los principales resultados.

**Síntesis de los datos:** Respecto al año de publicación, se percibió un aumento en el número de publicaciones referentes al área de los cuidados paliativos pediátricos. Respecto al tipo de estudio, cuatro artículos eran de revisión bibliográfica y cuatro eran investigaciones cualitativas. La principal forma de recolección de datos fue la entrevista semiestructurada. Los participantes de la mayoría de las investigaciones fueron los familiares del niño y los profesionales de salud. La principal patología tratada fue el cáncer y los enfermeros fueron los profesionales más citados. Los tipos de cuidado ofrecido se relacionaron a los aspectos físicos, a los cuidados generales y a los aspectos psicológicos, sociales y espirituales (menor énfasis). Los principales resultados encontrados fueron: poca énfasis en las necesidades de los niños, importancia de incluir a los familiares en el cuidado prestado y falta de preparación del equipo de salud.

**Conclusiones:** Aun siendo relatadas dificultades y desafíos para el establecimiento de los cuidados paliativos pediátricos, muchos artículos señalaron cuestionamientos y reflexiones importantes para el desarrollo de la práctica.

**Palabras clave:** cuidado del niño; cuidados paliativos; Brasil.

## Introduction

Palliative care in pediatrics is characterized by providing an active total care to the child, considering body, mind, and soul, as well as support to the family. In addition, palliative care is effective when there is a multidisciplinary team to promote the relief of physical, psychological, and social suffering of the child and can be offered in locations such as tertiary institutions, health centers, and even at home(1). In the palliative care approach, suffering can and should be relieved(2).

Palliative care begins at diagnosis and continues even if the subject receives a curative treatment or not. With the progression of the disease, there is an increasing applicability of palliative care, which extends to bereavement(3). This integration between curative and palliative treatment improves care coordination, avoids fragmentation(3), besides offering the maximum emotional, social, and spiritual well-being for the child and the family(4).

Palliative care applies to six conditions: children in whom curative treatment is possible (palliative care in times of uncertainty or failure to cure); children that need long-term intensive treatment; children for whom there is no hope of improvement, being the goal of the treatment totally palliative, and likely to last for years; children with severe neurological damage, leading to an increased vulnerability and increased complications; newborns with limited life expectancy, and family members of children who have had some trauma, sudden infant death, or early death of the newborn(5).

Scientific research on pediatric palliative care is a challenge due to the heterogeneity of the population, the uncertain outcome, the lack of knowledge, lack of institutional and financial support, the child's vulnerability and inadequate research designs(6). Furthermore, little is known about the national reality in this theme. Thus, we perceive the need to verify what is the reality of Brazilian research in the field of pediatric palliative care. Therefore, the aim of this study was to describe what has been published in Brazil on pediatric palliative care.

## Method

The present study is a descriptive literature review. We used the Lilacs and SciELO databases, searching for the keywords "palliative care", "child", "pediatrics", "terminally ill" and "death." The descriptors were interspersed with each other, and we selected Brazilian articles from January 2002 to December 2011.

Of the 67 articles found, 59 were discarded because they did not present palliative child care as the main subject, were repeated, or because the article was not available in full. The eight selected articles were organized into files containing identification data and the studied variables. The following

**Chart 1 -** Summary of results

| Article | Type of study | Population | Summary of main findings |
|---|---|---|---|
| Piva *et al*, 2011(15) | Literature review | Children with irreversible disease | - Professionals involved in the care: physicians, nurses, social workers, psychologists, chaplains, physical therapist, and occupational therapist<br>- Types of care offered: Therapeutic priorities (analgesia and sedation), supportive, fraternal environment, and privacy<br>- Decisions regarding end of life centered on medical opinion and little family involvement (lack of knowledge and training in both the medical undergraduate school and residency)<br>- Sincere dialogue with family members about the diagnosis, prognosis, therapy, and palliative care. This dialogue should be gradually established, meeting the needs of children in the final stages of life<br>- The success of palliative treatment depends on the treatment centered on the welfare of the child, with full participation of the family, not forgetting to provide family support after death |
| Rabello and Rodrigues, 2010(10) | Qualitative research with content analysis (semi-structured interview) | 18 members of 9 families of technology-dependent children | Professionals involved in care: multidisciplinary team (nonspecific)<br>- Types of care offered: household long-term care, non-invasive procedures, support, and educational actions<br>- Positive aspects: bond established with the staff and support; knowledge of the family regarding the child's illness and the dynamics of the service used<br>- Negative aspects: difficulties in the implementation and continuity of the Interdisciplinary Home Care Program; impact of illness on socioeconomic character; poor communication with other levels of care<br>- Importance of staff training to deal with family members who suffer from physical and emotional instability<br>- Need to coordinate home care with the network |
| Costa and Ceolim, 2010(16) | Literature review | Children and adolescents with cancer | - Professionals involved in care: nurses<br>- Types of care offered: honest communication from the perspective of comprehensive care, home care, comfort, pain management, and symptom management; recreational activities, support to families in mourning<br>- Consider the particularities of pediatric palliative care<br>- To meet the biopsychosocial needs of the child/adolescent and his family<br>- Need of teamwork, dialogue, solidarity, compassion, support and relief of suffering by ensuring dignity and promoting quality of life |
| Floriani, 2010(8) | Literature review | Technology-dependent children | - Professionals involved in care: physicians and nurses<br>- Types of care offered: physical care (respiratory support, parenteral nutrition, peritoneal dialysis or hemodialysis, wound dressings, ostomy care and bedsores) and other care (home, intimate and with medication); guidance and information to caregivers about the most appropriate care<br>- Obstacles: structural difficulties of households; difficulty referring children to pediatric hospitals; social isolation of the child and the family; disbelief by the health team; hyper medicalization of the home; uncertainty of a terminal prognosis; physical, emotional, social, material and financial overload of the family members; modifications in family organization and redefining roles<br>-Importance of continuing education pediatricians in care at the end of life<br>- Need of good partnership between the staff, the family, and the child |

Continue...

**Chart 1 -** Continuation

| Article | Type of study | Population | Summary of main findings |
|---|---|---|---|
| Poles and Bousso, 2009(7) | Literature review | Children in Intensive Care Units (ICU) | - Professionals involved in care: multidisciplinary team (doctor, nurse, social worker, psychologist and spiritual)<br>- Types of care offered: support; guidance; clarifications; approach to biological, psychological, social and spiritual dimensions of the child and the family; bereavement counseling; analgesia; management of pain and symptoms of discomfort.<br>- Attributes of the concept of dignified death: quality of life; knowledge about palliative care; pain management and symptoms of discomfort; welcoming environment; shared decision making; respect for cultural diversity<br>- Few articles brought the definition of decent death for the child<br>- The concept of decent death is still not consistently defined, requiring studies in clinical practice<br>- Need to include the topic of death in the curriculum of health professionals for a new approach in care at end of life |
| Avancini *et al*, 2009(17) |  | 5 pediatric nurses | - Professionals involved in care : nurses<br>- Types of care offered: comfort to the child; improving the quality of life, fostering decent death; providing welfare beyond the pathophysiological functions; analgesia, hygiene, relief of respiratory distress; caring for parents and family<br>- Discomfort of some nurses in dealing with death, with feelings of attachment, anxiety, failure, sadness, discouragement, helplessness and defeat<br>- Importance of relating the perception toward the child with cancer in palliative care for the feelings and emotions of nurses<br>- Nursing is aimed at promoting the comfort, relief from pain and symptoms, to meet the biopsychosocial and spiritual needs, and supporting families<br>- The need to emphasize the importance of nursing care in palliative care with the child with cancer<br>- The approach to the subject should be more widespread to better prepare professionals<br>- The need for a continuous service for professional psychological support |
| Costa and Lima, 2005(11) | Descriptive-exploratory qualitative study (semi-structured interview) | 26 nursing professionals who work in pediatric care | - Professionals involved in the care: nursing staff (nurses, technicians, and assistants)<br>- Types of care offered: positive interaction with the child; care of the child's physical needs<br>- The professional lives loss and mourns with the child's death with whom he formed a bond<br>- Feelings expressed by professionals: defeat, disappointment, sadness, pain, helplessness, and anger<br>- Need for emotional support to professionals<br>- Importance of the inclusion of the theme of death in curricula and conducting continuing education in schools and hospitals |
| Bolze and Castoldi, 2005(18) | Case Study | Family who lost a 4-year old daughter, which was fighting against cancer | Professionals involved in care: psychologist<br>- Types of care offered: home visits, strengthening of adaptive defense mechanisms and healthy aspects; guidance, support, and listening; bereavement counseling<br>- Necessity of theoretical support for the psychologist to conduct his activities successfully<br>- Importance of family religiosity for preparing for the child's death<br>- Authors' tips: groups for bereaved relatives<br>- Importance of psychological support by the hospital |

items were evaluated, according to the year of publication: type of study, form of data collection, participants, pathology, professionals involved in the care, types of care offered, and main results.

## Results

The selected articles were analyzed according to the criteria previously defined and are presented in Chart 1.

## Discussion

Regarding the year of publication, we noticed an increase in the number of studies related to the field of pediatric palliative care in the period of literature review. From the 1990s, there seems to be a growing interest in issues relating to the end of life, whether through discussions on the maintenance of life at any price, or by discussions of topics related to bioethics(7). The implementation of pediatric palliative care has many challenges due to the large number of clinical situations involving children and the need for the continued use of technology to keep their lives(8).

As for the types of study, four articles were literature reviews, three were qualitative studies, and one was a case study. Therefore, we observed that there is a movement to better understand palliative care and their interfaces, due to the greater number of review articles. We also observed the absence of quantitative studies. In the process of knowledge construction, the researcher should use both the qualitative and the quantitative approaches appropriate to the object of survey(9).

The semi-structured interview was the main form of data collection(10,11). The open interview and the search for articles on bibliographic databases were also used. The choice of the appropriate instrument, which will be used in scientific research, is complex and crucial, given the need for attention to the research objectives(6). In this sense, the research in the area of palliative care must obey certain principles, such as: ensuring the interests of the patient, conducting a pilot-study to ensure the results, obtaining permission from the Research Ethics Committee, and allowing flexibility in monitoring patients, ensuring no invasion of privacy or worsening of symptoms(12).

The target-population of selected articles consisted of children (in the articles of literature review), family members of children in palliative care, and nursing professionals (nurses, technicians and assistants). In the analysis we observed the importance of providing palliative care not only for the children, but also for the family and the healthcare team, as they are important actors in this dynamic. However, no studies presented the child in palliative care as a subject of research, except for the articles of literature review. The amount of researches with families and health professionals can be explained by the level of accuracy and care that researchers need to have when developing research with children. When such studies are conducted, it is important that the researcher presents himself with an approaching attitude, turning the moment of data collection into something that is easily understood by the child. Thus, the researcher has to be well organized, using a simple language, preparing the location of data collection, and remaining on the same level as the child, showing that he or she is working together with the investigator, who should also explain the goal of the research in a simple way, encouraging the child to talk freely, being attentive to what he or she says, tolerating their silence, using reflective responses to show empathy and understanding and respecting their cognitive, emotional, and social skills(13). Moreover, most children in palliative care are already greatly weakened and with difficulty in communicating verbally, which makes it harder to conduct research. This is because, in many institutions, there are still obstacles to establishing palliative care from the diagnosis of a potentially fatal disease, meaning that care is implemented only in terminal stage.

Concerning diseases, malignancies and chronic diseases were the most mentioned in the articles. Although some articles addressed other diseases, it was noted that the target-pathology of researches is still cancer. There was an increase in the number of articles and research projects in the field of oncology through the association of medical research with basic research, to generate national knowledge on specific issues(14).

The professionals involved in health care are doctors, nurses, technicians, nursing assistants, social workers, psychologists, spiritual advisors, physiotherapists, and occupational therapists. The professionals who were most mentioned in the articles as important in child palliative care were the nursing professionals, followed by doctors. Of the eight articles, only two mentioned other professionals involved in the care and one cited a multidisciplinary team, but did not specify which professionals formed it.

The expressiveness of nursing publications in this literature review is demonstrated by the fact that, of the eight selected articles, four were published in journals from this field. The fact that the physician is often cited in publications in the area of palliative care can be explained, as he is the legal responsible for the patient, and the one that responds directly to the bioethical dilemmas that arise(7). We observed the need for other professionals to publish and show their importance within the health team, once their performances in palliative care are indispensable. The team plays a major role for children in palliative care, preventing avoidable suffering through proper symptom management and decision-making(4). It is noteworthy that no article mentioned the role of nutritionists, speech therapists, music therapists, and dentists, among other members of the health team who play an important role with children and their families in palliative care.

The studies assessed mentioned several types of care offered to patients, such as: care related to physical aspects (parenteral nutrition, peritoneal dialysis or hemodialysis, healing of wounds, bedsores and ostomy care, supplemental oxygen or noninvasive ventilation care, physical comfort of the child, relief of pain and other physical symptoms, sedation), general care (home, intimate, and medication care), and related to psychological, social, and spiritual aspects (supportive psychotherapy, assistance to parents and family in decision making, with honest communication and the prospect of comprehensive care, play activities, support, guidance, clarification, individualized care, active listening, shared decision-making, organization of the environment, respect to the child' and the family's privacy, improvement of quality of life, favoring a decent death and bereavement support for family members). Of the eight articles selected three were restricted to pathophysiological care issues(8,10,11), four focused on comprehensive care(7,15-17), and one emphasized palliative care in the context of mourning(18).

The healthcare professional should provide a humane and integrated care, meeting the psychological, social and spiritual needs of the patient(17), besides the pathophysiological ones. It is necessary to expand the understanding of the human being beyond the biological dimension(19). The care of children and their families during the final stage of life is a challenge and a privilege, and there may be a major impact on the family experience and the adjustment of the parents after the child's death(7). Thus, we observed that bereavement support is essential, a fact that could have been further discussed in the articles of this review.

Only one article mentioned the importance of play for children in palliative care. The disease generates the removal of the child from their family environment, their daily habits, their routines, and their pleasurable activities. When the child relives daily situations during play, for instance, she forgets about her suffering(20). Playing is an important therapeutic tool for the development of the child and appears as a facilitator, helping the child to overcome the limitations of the illness(21). Thus, playing enables the expression of feelings and helps the child to see his or her process of elaboration of his illness condition more easily(22).

Two articles have cited the importance of the spiritual aspect in pediatric palliative care, but did not develop the subject(7,15). The spiritual issue at the end of life is difficult to approach due to the lack of knowledge by health professionals about their own spirituality and the patient's difficulty in recognizing his finitude(23). The spiritual dimension comprises everything that gives meaning to a person's life, relating to the transcendental(19). Spirituality relates to improved quality of life, less depression and stress, greater treatment adherence, better functioning immune system and greater ease to deal with problems(24).

To better discuss the results found in the articles, we decided to divide them into four main guiding sections: aspects related to the child, aspects related to the family, aspects related to the health team, and other relevant characteristics.

For the aspects related to the child, some important points were observed, such as the importance of meeting their biopsychosocial needs, ensuring dignity, promoting quality of life and a decent death, and preserving their autonomy; we also observed the social isolation experienced during the disease process and the hospitalization from birth in cases of congenital diseases or diseases that have manifested soon after birth. We noticed little emphasis on the description of children's needs in palliative care. The child is erroneously seen as someone who does not need special care or attention, since it is a human being who is starting life(17). Thus, death becomes a painful process for both the child and his or her family. Death or its proximity stimulates pain and other types of suffering and leads to reflection on feelings and spiritual/existential aspects of life(25). To avoid or deny death is to walk towards the denial of an integral aspect of human life(26), so the approach of this theme is required(16). It is, therefore, necessary to ensure dignity and to promote the child's quality of life, respecting their individuality and stimulating their serenity before death, promoting the humanization of care(16).

Concerning the aspects related to family members, we found the following information: need to care for family members; importance to meet the biopsychosocial needs of the family; physical, material, emotional, financial, and social overburden; feelings of loss of family members due to the possibility of death and denial of the incurability of the disease, leading to comorbidities such as hypertension, obesity, depression and sleep disturbance; other experienced feelings, such as attachment, anxiety, failure, sadness, discouragement, helplessness and defeat; difficulty by the family in communicating the truth to the child. Many of the needs of family members mentioned in the articles may be met with proper care through attentive listening, acceptance and relief of physical, psychological, social, and spiritual suffering. The safety and reliability of the family come especially from information received during the process of death, which needs to be offered in due course according to family demands(7). We observed that pediatric palliative care is not limited to the child's life period. It is necessary to emphasize that such care should be extended beyond the death of the child, since the family will be in need of support(15). With the child's death, actions must be taken to provide a less painful experience for families, conveying the news of death and preparing the environment properly, besides ensuring the privacy and the respect to the time required for the farewell. While the focus of care remains only in the child, family demands will not be analyzed, especially in relation to the expression of their feelings(27).

With regard to aspects related to the health care team, the relevant points are: the need to take care of the team, the physical and emotional exhaustion, the lack of continuing education by pediatricians, and the need to include the theme of death in the curriculum of these professionals; unpreparedness to give bad news, difficulty in managing children late in life, improper attachment of professionals, difficulty of living bereavement, and lack of staff training to deal with family members. Through the results found with the health team, it became clear that this difficulty in acting in the area of palliative care is due to the lack of preparation and the physical and emotional exhaustion. Consequently, these factors can lead to work-related stress or burnout syndrome. Thus, the following problems may occur with these professionals: lack of psychological support, stress with the possibility of death, lack of preparation to deal with the family, feeling of hopelessness, helplessness, or abandonment, among others(28). Hence, there is the need to care for those who provide care.

Often, the healthcare team is concerned only with the technical aspects of care, and this lack of preparation affects the integral approach and the perception of their own emotional state(29). While the goal of health professionals is only to clarify the diagnosis and to treat physical symptoms, there will be a failure in the proper prevention and treatment of suffering(2). This fact can be explained by the reductionist and positivist views that many health professionals have(2) and by the lack of professional training to deal with children and their families in palliative care. Thus, it is essential to prepare the staff and to offer courses and specializations in palliative care.

In relation to other relevant characteristics, the following aspects were found: need for good partnership between staff, family, and child; importance of avoiding therapeutic obstinacy; definition of well-defined objectives, individualized needs, and anticipating events; difficulties in referring children to palliative care units; care still centered in healing; disbelief in the available therapeutic measures; structural difficulties of the household and access to home care, community difficulties of non-acceptance; hyper medicalization of the household; ineffective palliative home care programs to treat children and their families; lack of coordination of palliative care at home with other levels of care. These relevant features indicate that there are still many difficulties to establish pediatric palliative care. This last guideline was characterized, in most of the papers, by aspects related to home care. The difficulties and problems encountered in the structuring of palliative care at home demonstrated disrespect to the right to health, besides the conflict between the discourse of the Ministry of Health for the deinstitutionalization and humanization and what is actually found in practice(10).

Children with serious illnesses and poor prognosis create ethical dilemmas in health teams, and it is difficult to differentiate the care and relief of suffering (with comfort and decent death) from the use of invasive and painful procedures arising from technological progress, which only prolong the suffering(7). Thus, it is worth noting that pediatric palliative care is progressively implemented and according to the needs arising from the disease and treatment. It should also be individualized to each child, considering the values and desires of the binomial family-patient(15). Still, some articles showed the effort to understand pediatric palliative care, discussing the main aspects for its implementation.

Regarding the limitations of the present research, we realized that there was no comparison of Brazilian data with international data, which would provide greater understanding of the reality of palliative care in Brazil. Moreover, the description of each study was limited to published data, with no attempts to contact the authors to clarify doubts and confusing information. In this sense, we recommend further literature reviews containing complete data, through contact with the authors of the analyzed studies.

Despite the increase in the number of Brazilian publications in pediatric palliative care, there are still few studies with more methodological rigor and adequate sample sizes. The majority of research participants were children's parents and caregivers, who demonstrated difficulties in addressing the diseased child. It is essential to consider other diseases besides cancer and the importance of reporting all staff to humanize health care.

There is difficulty in addressing comprehensive care in pediatric palliative care, and despite the fact that it was mentioned in some studies, the subject was not studied in depth. Therefore, it is necessary to value this kind of care, emphasizing not only the physical aspects but also the psychological, social, and spiritual ones. We also observed some difficulties by health professionals in dealing with issues related to the care of the family, the child, and with their own care, causing a lot of physical and psychological stress. Therefore, training and continuing education are essential.

Even though studies pointed out difficulties and challenges in establishing pediatric palliative care, many authors brought up important questions and considerations for the development of the practice, which demonstrates an advance in the Brazilian reality.

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