

Palliative care in pediatrics: a review

Maria Thereza Macedo Valadares¹, Joaquim Antônio César Mota², Benigna Maria de Oliveira³

Abstract

The technological expansion in recent decades changed the profile of the patients in pediatrics, with assistance to children with chronic and life-threatening conditions more frequent each time. Palliative care involves an active and full assistance provided to these children, in the context of their body, mind and spirit as well as the support offered to their entire family. This study provides a review of relevant aspects in palliative approach: the prevalence and approach of symptoms, the participation of a multidisciplinary team, communication with family, care at end of life and limitation of invasive therapies. Despite recognition of the importance of palliative medicine, our universities still give priority to curative medicine. Introducing this theme in the process of medical education is a real and absolute need, aiming to provide dignified life and death to our patients.

Key words: Palliative care. Pain. Assistance. Child.

Resumo

Cuidados paliativos em pediatria: uma revisão

A expansão tecnológica das últimas décadas modificou o perfil dos pacientes na pediatria, tornando cada vez mais frequente a assistência a crianças com doenças crônicas e ameaçadoras à vida. Cuidados paliativos envolvem a assistência ativa e total prestada a essas crianças, nas dimensões de seu corpo, mente e espírito, bem como o suporte oferecido a sua família. O presente estudo revisa aspectos relevantes na abordagem paliativa: a prevalência e abordagem dos sintomas, a participação de equipe multiprofissional, a comunicação com a família, os cuidados ao final da vida e a limitação de terapêuticas invasivas. Apesar do reconhecimento da importância da medicina paliativa, nossas universidades ainda priorizam a medicina curativa. Instituir esse tema no processo de formação do médico é uma necessidade real e absoluta, visando proporcionar vida e morte dignas aos nossos pacientes.

Palavras-chave: Cuidados paliativos. Dor. Assistência. Criança.

Resumen

Los cuidados paliativos en pediatría: una revisión

La expansión tecnológica de las últimas décadas ha cambiado el perfil de los pacientes de pediatría, volviendo cada vez más frecuente la asistencia a los niños con enfermedades crónicas y potencialmente mortales. Cuidados paliativos involucran la asistencia activa y total prestada a estos niños y niñas, en el ámbito de su cuerpo, mente y espíritu, así como el apoyo ofrecido a toda su familia. Este estudio proporciona un análisis de los aspectos relevantes en el enfoque paliativo: la prevalencia y abordaje de los síntomas, la participación de un equipo multidisciplinario, la comunicación con la familia, la atención al final de la vida y la limitación de las terapias invasivas. A pesar del reconocimiento de la importancia de la medicina paliativa, nuestras universidades siguen dando prioridad a la medicina curativa. Establecer ese tema en el proceso de la educación médica es una necesidad real y absoluta, con el objetivo de proporcionar una vida y una muerte dignas a nuestros pacientes.

Palabras-clave: Cuidados paliativos. Dolor. Atención. Niños.

1. **Master** therezaval@yahoo.com.br 2. **Doctor** jacmota@uol.com.br 3. **Doctor** benigna@uol.com.br – Federal University of Minas Gerais, Belo Horizonte/MG, Brazil.

Correspondence

Maria Thereza Macedo Valadares – Rua Grão Pará, 926, apt 404, Funcionários ZIP 30150-341. Belo Horizonte/MG, Brazil.

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The technological expansion in recent decades led to the development of all areas of health care, changing the profile of patients and diseases. In pediatrics, the technological advancement has brought undeniable progress in all specialties. In neonatology, premature infants and newborns with low weight have presents increasing survival rates. In infectology, diseases once thought to be prevalent and severe are uncommon today, thanks to modern medicine and vaccinations. In oncology, the emergence of new therapy allowed significant reduction in mortality of children with cancer ¹⁻³.

However, despite the technological apparatus, some children still live in conditions that threaten life: as patients with severe sequelae or who need special care or, in some cases, do not meet the established modern treatments for their diseases ^{1,3}. Dealing with this new profile of pediatric patients requires a different approach. Even when there is a curative treatment, palliative care shall and must be implemented with the main objective of providing better control of symptoms and improving quality of life for children and their families.

In 1998, the World Health Organization (WHO) presented a specific definition for palliative care in pediatrics: active and full assistance provided to children in the context of their body, mind and spirit, as well as the support offered to the entire family ⁴. According to the WHO, palliative care should be initiated when the chronic disease is diagnosed, and should walk concomitantly with curative treatment.

The assessment and relief of suffering are priorities in this approach and should exceed the biological field, reaching the social and psychic spheres. To make this really possible, the WHO states the need for a multidisciplinary team that includes, in the process, the whole family and the environment in which the child is inserted. Such care can be provided in primary care centers, tertiary and even in the child's home ⁴.

Himmelstein highlights some basic principles for children's palliative care: care is child focused and family oriented, all built in a good staff-family relationship. Each child shall be individually assessed, as well as their families, respecting their beliefs and values, and facilitating communication. Such care shall be extended after death, during the family's grieving. Every child who has a diagnosis of a chronic illness that threatens life should receive palliative care.

The author states that these conditions may fall into four broad categories: 1) conditions in which

curative treatment is possible, but there may be therapeutic failure, such as patients with oncological diseases, 2) conditions that require long term treatments, with the goal of improving the patient's quality of life, as in cystic fibrosis, 3) known progressive diseases, with only palliative treatments, such as trisomy 13 and 18 and, 4) serious conditions, not reversible, but that would imply much vulnerability, as children with secondary cerebral palsy due to acute fetal distress ⁵.

For good care of these children, interventions should not be limited to specialists in palliative care. General pediatricians and other physicians from several areas, such as oncologists, hematologists and neonatologists, can effectively perform this care through knowledge of the needs of the child and his family and recognition of the importance of a multi and interprofessional work aimed at controlling pain and other symptoms, and also individualized, full attention to each patient ^{5,6}.

Method

The work is based on literature review, using articles indexed on the basis Lilacs and Medline, via Pubmed. In Medline, we have used the following descriptors: "Palliative Care" and "Hospice Care", with filters "all Child" and "Infant". The search strategy was: ("Palliative Care"[Majr]) OR "Hospice Care"[Majr] AND ("infant"[Filter] OR "all child"[Filter]). In the base Lilacs, the search strategy was: "Palliative Care" OR "Hospice Care" OR "Care to Terminally Ill Patients" OR "Palliative Care to Terminal Patients" OR "Comfort Care" OR "Intermittent Care Programs" OR "Palliative Care Programs" OR "Palliative Assistance" OR "Atención Paliativa" OR "Cuidados Paliativos" OR "Palliative Treatment", also with a limit for the pediatric age group. The research has been conducted as the discussion on the topic was intensifying, and new studies appeared in specialized journals. The survey was accomplished in a systematic way, including studies published between January 2000 and October 2012.

Only articles relating to pediatrics were included in this study, in Portuguese and/or English, and we excluded the articles that were limited to neonatology and those whose term palliative did not refer to care, but to palliative treatments – such as palliative cardiac surgery. According to these criteria, 576 articles were identified. All abstracts were read and discussed by the authors, who selected the most relevant articles. Furthermore, a verification of refe-

rences cited in the selected articles was performed. Finally, 29 articles were used for this literature review. Additionally, we used the Palliative Care Manual of the National Palliative Care Association, the current Code of Medical Ethics (2010) and the electronic *website* of the World Health Organization (WHO).

Prevalence and approach of symptoms

The impeccable control pain and other symptoms is the main strategy in the management of children needing palliative care. But there is little research on the management of pain and symptoms in pediatric palliative care, especially when compared to the extensive range of studies relating to adult patients⁵. Consequently, many of the current recommendations are extrapolated from the adult world to children's.

Added to this gap is the fact that there are many children with palliative care needs, but most studies are limited to the management of prevalent symptoms in children with cancer⁵. Wolfe *et al* have evaluated the symptoms of children with cancer who died between 1990 and 1997, at Dana Farber Cancer Institute and the Children's Hospital of Boston. The parents of 102 children who died in that period were interviewed. Among these, nearly 80% died due to disease progression, while the others died due to treatment-related complications.

In this study, according to the parents, 89% of children had significant distress in the last month of life, this suffering secondary to at least one symptom, being the most prevalent pain, fatigue and dyspnea. Among children who had specific treatment for the symptoms, the treatment was effective in only 27% of children with pain and 16% of those with dyspnea. Parents reported more symptoms than those recorded in the medical records⁷.

In 2008, Wolfe compared the symptoms' prevalence of children of the above study with 119 children who subsequently died, also secondary to neoplasms, between 1997 and 2004. The proportion of children with symptoms such as fatigue, pain, dyspnea and anxiety did not differ between the two cohorts. However, according to the parents, there were fewer reports of significant distress secondary to pain, dyspnea and anxiety, suggesting a better approach of symptoms by medical staff⁸.

A similar study was conducted in Australia at the Royal Children's Hospital of Melbourne, with questionnaires which assessed parents' reports regarding symptoms of children who died

of cancer between 1996 and 2004. Among the 96 families interviewed, 84% reported intense distress experienced by the child in the last month of life, related to at least one symptom: pain (46%), fatigue (43%) and hyporexia (30%) were the most prevalent. Among the children who received treatment, only 47% received adequate pain control, 18% fatigue control and 17% hyporexia control⁹.

In the Netherlands, Theunissen *et al* conducted between 1999 and 2002 a retrospective study including parents of 32 children who had died with terminal cancer, in order to verify the physical symptoms and psychological factors in these patients¹⁰. The findings are comparable to the study of Wolfe⁷ and John A. Heath⁹. According to parents, 82% of physical symptoms were addressed by the medical staff. However, only 18% and 26% of these symptoms showed complete or partially complete improvement, respectively, after medical management. Psychological symptoms were less addressed by the medical staff (43%) and after approach, only 9% and 25% presented complete or partial improvement, respectively¹⁰.

For these studies it is evident the need for a more effective approach to the control of prevalent symptoms in children, aiming to achieve the optimal management of palliative care. Methodological limitations, secondary to the retrospective design of the studies, shall be considered. Moreover, in the aforementioned studies the perception of symptoms and appropriate management was limited to the observation of the parents, which may not match the perception of the child's doctor or even the child's perception itself^{7,9}.

In 2004, Brian S. Carter conducted a descriptive study on the medical care provided to terminally ill children. A hundred five children who were hospitalized at the time of their death were included in the study. The data were obtained from reports of medical records relating to the last 72 hours of the child's life. Among the most frequently reported symptoms there were pain (34%) and dyspnea (24%). The authors also highlighted the difference between the medical record of symptoms and their respective approach. Regarding pain, approximately 90% of the children were prescribed analgesia. Regarding dyspnea, only half of patients with this symptom received specific treatment. In patients with prolonged crying and fatigue, only a minority received treatment¹¹.

Ross Drake also assessed the prevalence of symptoms by registering medical records. In this

study, we have included thirty children who subsequently died in Children's Hospital at Westmead, Australia. The average number of symptoms per patient in the last week of life was 11 ± 5.6 , and six symptoms presented a prevalence of above 50%: fatigue, somnolence, skin changes, irritability, pain, and lower limbs edema ¹².

Collins *et al*, in turn, used a rating scale (Memorial Symptom Assessment Scale – MSAS) to determine the prevalence of symptoms in 159 children with cancer, aged 10 to 18 years, from the patients' own reports. The most prevalent symptoms (above 35%) were fatigue, pain, somnolence, nausea, cough, decreased appetite and psychological symptoms (sadness, nervousness, worry, irritability). The authors found no significant difference in the prevalence of symptoms by age or gender. Pain was the most prevalent symptom in the group of hospitalized patients (84%), considered very distressing for 52% of children ¹³.

Regardless of study design, it is observed a high prevalence of symptoms in children requiring palliative care, especially near the time of death, when these are mandatory. The parents' report is a valuable tool to address the symptoms, but whenever it is possible, the child's report must be obtained, as it is considered the "gold standard" for the determination of symptoms ⁶.

In 2010, Jeffrey C. Klick and Julie Hauer described important conditions for the management of prevalent symptoms in pediatric palliative care. According to the authors, a partnership between medical staff and parents/children is essential to clarify the benefits and side effects of medications, focusing on the best possible quality of life for the patient. To control symptoms, non-pharmacological treatments (such as music therapy, acupuncture, games, massage) can be useful, especially if associated with the pharmacological measures ⁶. The authors highlight the importance of the holistic approach of symptoms (emotional, spiritual and social), given that it can increase the success of treatment ⁶.

Anticipating symptoms, acting timely and reviewing frequently the result of the approach of those symptoms are also important principles ⁶. It is known that the ineffective management of the symptoms presented by children is directly related to their substantial suffering in the last days of life, which is experienced by the family and the patient ^{7,9}. To optimize such assistance is the key point of palliative care.

Multidisciplinary team and communication with family

Currently, palliative care is closely linked to curative care, with a focus on the integral approach to the child and its family. This comprehensive care requires the participation of a multidisciplinary team including doctors, nurses, social workers, physiotherapists, occupational therapists, religious, among others ¹⁴. Children with various diseases may benefit from palliative care and, consequently, professionals from various fields will provide such assistance to their patients ^{15,1}.

It attests to this assertion a retrospective review held in Canada, which evaluated seven pediatric palliative care programs and a children's hospice. Most patients in these programs had presented as a primary diagnosis neurological disorders (39.1%), followed by malignant tumors (22.1%) ¹⁵. A study in six U.S. and Canadian pediatric hospitals, with 515 children, has also shown that the predominant clinical condition was genetic/congenital malformation (40.8%), followed by neuromuscular diseases (39.2%), cancer (19.8%), respiratory diseases (12.8%) and gastrointestinal diseases (10.7%) ¹⁶. In both examples, the majority of patients were dependent to medical technology, and the use of gastrostomy (48.5%) was the most common form ¹⁷.

In the literature, there are few studies that evaluate the participation of a multi and interdisciplinary team in palliative care in pediatrics. In a retrospective study, Brian Carter assessed the circumstances of the death of 105 hospitalized children, especially in relation to the control of symptoms and the involvement of a multidisciplinary pediatric team. During the last hospitalization of those patients, the multidisciplinary approach was not documented as often ¹¹.

In 2009, Monterosso conducted an interview on palliative care with 69 parents of children who had died of cancer. He has concluded that those children and their families' care shall be coordinated by a multidisciplinary team and that it is necessary the integration between primary and tertiary care services ¹⁸. Several experts in pediatric palliative care have recommended the participation of professionals from various fields in the health care of children with chronic illnesses. Due to their specific knowledge, each team will make specific approaches, helping to reduce the suffering of children and their families. But clear communication between team members and the child/family is necessary so that this approach is effective ⁶.

Helle and Solomon interviewed the parents of 36 children with life threatening illnesses, who died in three university pediatric hospitals in the United States. For these parents, the presence of a consistent team throughout hospitalization favored the good relationship between the family and medical professionals¹⁹. In a study by Jennifer W. Mack *et al* it has been evaluated, from the perspective of parents and physicians, the quality of health care provided to children with cancer in the final stage of their lives. According to parents, the communication between doctors and the family was considered as the most relevant factor in determining the quality of medical care²⁰.

In another study, the quality of the medical staff communication was evaluated from the perspective of parents and also children's. Twenty children and adolescents were included in the study, with mean age of 14.25 years, with a survival possibility of less than 20% within the period of three years. Parents and patients have identified that communication between doctor and family/child is the key to building a good relationship²¹.

Meyer *et al* have identified priorities for pediatric care in the final stage of life with limited invasive therapy, by including 56 parents of children who died in a study; and they found similar responses: complete and true communication, easy access to medical staff, feelings were experienced and demonstrated by the medical staff, preservation of integrity of the parent-children relationship, and faith²².

Robert J. Weidner says that in this last decade there has been a cultural change in medical practice: a paternalistic approach was replaced by another way of dealing with the relationship, which recognizes the role and importance of the family and the patient. In the author's opinion, the pediatric palliative medicine shall recognize patient and family as a care center unit²³. Consistent with this new criterion, the Committee on Bioethics and Committee on Hospital Care of the American Academy of Pediatrics (AAP) believe that pediatricians should support parents and siblings of children with chronic diseases, since everyone is affected by the disease process.

This committee also emphasizes that both doctors and parents shall talk with the sick child about their feelings, fears and anxieties. The development of the child, their previous experiences with death, religion and cultural aspects of the family are factors that must be considered to make this communication effective. To avoid this type of communication is to ignore the fact that the sick children, most often, are aware of their situation. For the American

Academy of Pediatrics, limitation of futile therapies does not mean to wish or anticipate the death of children, but to promote a dignified death, without pain and distress¹⁵. Feudner notes that the development of communication skills will benefit not only patients and family members but also the medical staff itself²⁴.

Palliative care at the end of life and limitation of invasive therapies

The American Academy of Pediatrics advocates the integrated model of palliative care: the components of palliative care are offered at diagnosis and continue throughout the course of the disease, whether the final stage is cure or death¹⁷. Monitoring the family during the process of death and grieving, as well as providing support for the whole team, are also palliative care actions^{1,15}.

With the progression of the disease and the consequent reduction of curability, palliative care takes an upward curve, becoming an absolute necessity²⁵. Therefore, assuming that there is no place for palliative care until curative measures are exhausted can interfere with an early approach of sensitive issues, such as the limitation of invasive therapies at the end of life¹⁵.

Jennifer Mack states that invasive medical approaches are still part of the care of children affected by a progressive disease with no possibility of cure, even near to death, and that the early integration of palliative care in the disease course facilitates the preparation of the family for death. According to the author, among the possible reasons that justify the persistence of invasive measures at the end of life is the challenge for doctors to predict death, i.e. to recognize, according to the trajectory of the disease, whether or not death is near. Another plausible explanation would be an inadequate communication with family/patient²⁶.

In a study performed with 107 physicians, 71% stated that discussions on issues related to the health care planning for children with life threatening diseases occurred late. Doctors have also identified the main barriers that hindered these discussions: unrealistic expectations of parents; different understandings about prognosis between parents/patients and medical staff, and lack of preparation of the parents to discuss such issues²⁷.

In Brazil, there is a fear on the part of some physicians regarding the possibility of limiting invasive therapies for patients with progressive dise-

ases. However, the current Code of Medical Ethics (CEM) ²⁸ explicit the physician's duty to provide palliative care to patients with incurable and terminal diseases, in several of its articles ²⁸.

Article 41, Sole Paragraph – In case of incurable and terminal illness, the physician shall offer all palliative care available without undertaking useless or willful diagnostic or therapeutic actions, taking into account the expressed wishes of the patient or, in their absence, to his legal representative ²⁹.

Tonelli *et al* have evaluated the profile of health care provided to pediatric patients who subsequently died in a university hospital. The authors analyzed 106 cases, and of these, 51.9% had limitation of life support, being more common the limitation of therapies in the neonatal unit and in patients with diseases limiting their survival ³⁰. A study conducted in three pediatric intensive care units in southern Brazil also showed that 36.1% of patients had limitation of life support, being observed the association between the limitation of life support and the chronic disease ³¹.

In 2007, the same group conducted a study on health care at the end of life in children in Brazil and worldwide. The authors state that there are differences regarding limitation of life support in various countries, which relate to religious, cultural, legal and economic factors. It is observed that in Brazil in recent years, there has been increased limitation of life support in pediatric intensive care units, from 6% to 40%, being the order not to resuscitate its most frequent form ³².

It is important to highlight, however, that in these studies of Tonelli and Lago family's involvement in decisions about limitation of therapies has corresponded to 20.8% and less than 10%, respectively ^{29,30}. However, Himelstein ⁵ highlights that the quality of care in pediatrics is related to the sharing of medical decisions between family, child and medical staff, which could be expected significantly higher percentages. The author emphasizes the need to also involve sick adolescents in this process of medical decisions whenever it is possible. The American Academy of Pediatrics also

supports the involvement of patients in medical discussions ^{15,33}.

Jefferson Piva ¹ published in 2011 a review article on the dilemmas and difficulties involving decisions regarding the end of life and palliative care in pediatrics. The author explains that, as proposed by Himelstein ⁵, decisions on limitation of futile therapies must be shared with the patient and family (as in the case of children and incapable patients).

The author suggests that the existence of a consensus among the medical staff responsible for the patient must be prior to involving family participation in the decision making process. Thereafter, Piva recommends that futile interventions shall be identified and excluded (actions that will not contribute to disease control and will not result in better quality of life for the patient), as well as certain individualized therapeutic priorities, such as optimization of analgesia. The author reports that medical procedures faced with possible occurrences/complications regarding the patient's condition must first be discussed with the family and clearly recorded in the medical records ¹.

Final Considerations

The literature shows that, currently, palliative therapy is no longer on the opposite pole of curative therapy. The integration of the two models can provide better quality of life for families and for children with chronic and life threatening diseases. To recognize and effectively treat the most prevalent symptoms in patients; attending multidisciplinary team in order to develop good relationships between medical staff, family and patients; and to discuss the issues related to the end of life are some basic fundamentals of palliative care.

Whether in primary or tertiary care, all health care professionals will handle this new patient profile. Thus, introducing this theme throughout the process of medical education, and specifically of pediatricians' education is a real and absolute necessity, which will benefit the whole team involved, but especially patients, contributing to dignified life and death.

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