

Repercussions of pediatric palliative care: an integrative review

Amanda Andrade Aguiar de Pinho¹, Isabel Regiane Cardoso do Nascimento², Igor Weyber da Silva Ramos³, Vanilla Oliveira Alencar⁴

Abstract

This article aims to discuss the effects of pediatric palliative care services on hospitals and the quality of life of patients and their families. The research reports the results of an integrative literature review based on 14 articles published between 2013 to 2018. In the studies analyzed, the following aspects were highlighted: efficacy of pediatric palliative care in hospitals, reductions of hospital costs after implementation of the service, importance of multidisciplinary teams, educational needs of health professionals, and the impact on the quality of life of patients and their families. Results show that pediatric palliative care provides comprehensive care and should be recognized as an indispensable and specialized service for children with incurable diseases.

Keywords: Palliative care. Pediatrics. Health services. Hospital care.

Resumo

Repercussões dos cuidados paliativos pediátricos: revisão integrativa

O artigo visa discutir os efeitos dos serviços de cuidados paliativos pediátricos sobre a instituição hospitalar e a qualidade de vida de pacientes e seus familiares. Para isso, o texto traz resultados de revisão integrativa de literatura que considerou 14 artigos publicados de 2013 a 2018. Nos estudos analisados sobressaíram os seguintes aspectos: eficácia dos cuidados paliativos pediátricos; diminuição dos custos hospitalares após a implantação do serviço; importância da equipe interdisciplinar; necessidades educacionais dos profissionais da saúde; e impacto na qualidade de vida de pacientes e familiares. Conclui-se que os cuidados paliativos pediátricos proporcionam cuidado transversal e devem ser reconhecidos como serviço especializado e indispensável para pacientes pediátricos com doenças incuráveis.

Palavras-chave: Cuidados paliativos. Pediatria. Serviços de saúde. Assistência hospitalar.

Resumen

Repercusiones de los cuidados paliativos pediátricos: revisión integrativa

Este artículo tiene como objetivo discutir los efectos de los servicios de cuidados paliativos pediátricos sobre la institución hospitalaria y la calidad de vida de los pacientes y su familia. Para ello, el texto presenta los resultados de una revisión integrativa de la literatura que incluyó 14 artículos publicados entre el 2013 y el 2018. En los estudios analizados destacaron los siguientes aspectos: la eficacia de los cuidados paliativos pediátricos, la reducción de los costos hospitalarios tras la implantación del servicio, la importancia del equipo interdisciplinar, las necesidades educativas de los profesionales de la salud; y el impacto en la calidad de vida de los pacientes y su familia. Se concluye que los cuidados paliativos pediátricos proporcionan cuidado transversal y deben ser reconocidos como un servicio especializado y esencial para los pacientes pediátricos con enfermedades incurables.

Palabras clave: Cuidados paliativos. Pediatria. Servicios de salud. Atención hospitalaria.

1. **Graduate (specialist)** amandaandaguiar@hotmail.com – Hospital Infantil Albert Sabin (Hias) 2. **Master** isabel.cardoso@hias.ce.gov.br – Hias 3. **Graduate** igorweyber10@gmail.com – Universidade de Fortaleza, Fortaleza/CE 4. **Graduate** vanilla.oliveira@hotmail.com – Hias, Fortaleza/CE, Brasil.

Correspondence

Amanda Andrade Aguiar de Pinho – Rua Bonfim Sobrinho, 540, apt. 701 A, Fátima CEP 60040-500. Fortaleza/CE, Brasil.

The authors declare no conflict of interest.

In the second half of the 20th century, scientific advances and therapeutic improvements made it possible to carry out early diagnoses. However, as a result of increased life expectancy, chronic diseases have become more prevalent. This trend draws attention to the suffering of patients with incurable diseases, bringing new demands to health services and changing the type of care to be provided to patients and their families.

Life-limiting or life-threatening diseases also affect children and consequently their families. These are often complex chronic conditions, that is, diseases that tend to last at least 12 months and severely affect body systems and organs. Such ailments require specialized pediatric care, with periods of hospitalization in tertiary care services, and are incurable progressive conditions, inevitably leading to death¹.

The World Health Organization (WHO)² recognizes that palliative care promotes quality of life by preventing and relieving the suffering of patients affected by life-threatening diseases. This type of assistance aims to treat pain and other symptoms, also providing psychosocial and spiritual support, which extends to family members^{2,3}. WHO² also considers palliative care in the pediatric context, including support and guidance for the child's family.

This end-of-life care is an interdisciplinary assistance that involves total, active and integrated care, implemented when the patient does not respond to treatments^{2,4}. Pediatric palliative care (PPC) starts when the progressive illness is diagnosed, according to the evolution of the clinical picture. Health professionals should evaluate each child and family individually, respecting beliefs and values, and facilitate communication. Death does not end PPC, which must continue during family mourning⁵.

In the pediatrics context, healthcare should be comprehensive, as children are people in development, who have the right of being protected by the State, especially when they are ill. Thus, health systems must have interprofessional teams that may offer comprehensive PPC with technical competence. Hospitals should assimilate this proposal and break with the paradigms focused only on diseases and protocols. They need to structure the immediate start of palliative care after the diagnosis of a chronic disease, concomitantly with any curative treatment, which may have no effect⁵.

Regarding the clinical-epidemiological profile of patients who demand PPC, the literature indicates a prevalence of congenital/genetic malformation, cancer, and neuromuscular, respiratory and gastrointestinal disorders⁵. Most of these patients depend on medical technology, and gastrostomy is the most common support, followed by dialysis catheter, chemotherapy and tracheostomy^{5,6}. A cohort study also highlights that, in a 12-month follow-up, 30.3% of patients ended up dying⁶.

The patient's family, in turn, tends to feel fear, guilt and anxiety about the treatment provided and their child's future, therefore also needing specialized care and more information about the situation. In this sense, the medical staff's performance in PPC must be interdisciplinary, with professionals from different areas monitoring the evolution and prognosis of the ill in inpatient units or during home visits.

But as an emerging specialty, PPC is still evolving. Many are the challenges to implement this type of assistance, such as the diversity of the pediatric population, uncertain prognosis, lack of knowledge, lack of institutional and financial support, patient vulnerability, and scarce scientific research on palliative care focused on this age group⁷. There is also resistance in defining the prognosis of terminality and the focus of the medical team on curative actions, relegating the child's biopsychosocial suffering to the background⁸.

Given the need to systematically implement PPC in hospitals, this study aims to discuss what factors influence this process and the repercussions of palliative care on the quality of life of patients and families.

Method

This is an exploratory qualitative study using an integrative literature review as a technical procedure. This method aims to gather and summarize research results on a given theme, as to allow analysis and contribute to clinical practice by deepening the knowledge of the topic⁹. We searched the Latin American and Caribbean Literature in Health Sciences (Lilacs) and Medical Literature Analysis and Retrieval System Online (Medline)/PubMed databases, using the following terms and their Portuguese equivalents: "palliative care" (*cuidados paliativos*), "pediatrics" (*pediatria*), "health services" (*serviços de saúde*) and "hospital care" (*assistência hospitalar*).

Full articles published in Portuguese or English and indexed between 2013 and 2018 were included. The texts could follow different methods, but they should describe the provision of palliative care in general pediatrics, characteristics of patients, and have conclusive findings. We excluded articles that were limited to addressing palliative care in pediatric oncology, as this context had already been widely explored, and those addressing the topic based on specific diseases. Publications other than articles (such as editorials, letters to the editor, etc.) were also disregarded.

The initial search resulted in 615 articles, whose titles and abstracts were read to eliminate texts outside the proposed theme. From this process, 60 articles were selected and read in full. Finally, considering the inclusion and exclusion criteria, 14 articles were chosen as the study sample.

Results

Table 1 lists the articles selected for the review, with respective authors, year of publication, title, objectives, and database.

Table 1. Sample characteristics

Authors/year	Title	Objectives	Database
Herbert and collaborators; 2014 ¹⁰	“Development of a state-wide pediatric palliative care service in Australia: referral and outcomes over two years”	To map the characteristics of the population cared for by the newly formed pediatric palliative care service in Queensland, Australia, and describe the development of the service for 24 months.	Medline/ PubMed and Lilacs
Verberne and collaborators; 2018 ¹¹	“Barriers and facilitators to the implementation of a pediatric palliative care team”	To identify barriers and facilitators reported by health professionals in primary, secondary and tertiary care when implementing a pediatric palliative care service that aims to integrate care in the hospital and in the patient’s home.	Medline/ PubMed
Verberne and collaborators; 2017 ¹²	“Parental experiences with a pediatric palliative care team: a qualitative study”	To obtain information, based on the parents’ perspective, on the support provided by a new pediatric palliative care team.	Medline/ PubMed
Smith and collaborators; 2015 ¹³	“Pediatric palliative care and inpatient hospital costs: a longitudinal cohort study”	To examine the relationship between hospitalization costs and pediatric palliative care.	Medline/ PubMed and Lilacs
Ananth and collaborators; 2017 ¹⁴	“Trends in hospital utilization and costs among pediatric palliative care recipients”	To assess hospital utilization and costs by comparing patients who receive pediatric palliative care with patients who do not receive them at the Boston Children’s Hospital.	Medline/ PubMed
Conte and collaborators; 2016 ¹⁵	“Pediatric palliative care program versus usual care and healthcare resource utilization in British Columbia: a matched-pairs cohort study”	To compare use of hospital resources between children receiving palliative care and children under usual care.	Medline/ PubMed
Gans and collaborators; 2016 ¹⁶	“Cost analysis and policy implications of a pediatric palliative care program”	To describe a palliative care program Partners for Children, created in California, addressing the political context of its development, and assess the effects of the initiative, considering its costs.	Medline/ PubMed
Jamorabo, Belani, Martin; 2015 ¹⁷	“Complex chronic conditions in Rhode Island’s pediatric populace: implications for palliative and hospice services, 2000-2012”	To describe mortality trends for children up to 17 years of age with complex chronic conditions in Rhode Island.	Medline/ PubMed and Lilacs
Ogelby, Goldstein; 2014 ¹⁸	“Interdisciplinary care: using your team”	To review the current structure of the palliative care team, showing opportunities to include other members and identifying challenges that arise when the group of professionals involved in the care of a child and their family expands.	Medline/ PubMed
Moore, Sheetz; 2014 ¹⁹	“Pediatric palliative care consultation”	To reflect on the benefits of aligning health team, patient and family, based on consultations in palliative care.	Medline/ PubMed and Lilacs

continues...

Table 1. Continuation

Authors/year	Title	Objectives	Database
Keele, Keenan, Bratton; 2016 ²⁰	“The effect of palliative care team design on referrals to pediatric palliative care”	To describe the structure of palliative care teams, assessing whether composition and availability are associated with utility, and examine reference standards.	Medline/ PubMed
Frizzola, Miller; 2014 ²¹	“Referrals to a new pediatric palliative care team: details of the first 12 months of operation”	To describe the patient population assisted by a newly created palliative care program, comparing it with the existing literature.	Medline/ PubMed and Lilacs
Benini and collaborators; 2016 ²²	“Barriers to the development of pediatric palliative care in Italy”	To highlight, via data and literature review, critical issues that prevent the planning and development of palliative care services in Italy.	Medline/ PubMed
Goldhagen and collaborators; 2016 ²³	“Community-based pediatric palliative care for health-related quality of life, hospital utilization and costs lessons learned from a pilot study”	To analyze results from unpublished evaluation studies carried out since 2007, which shows the impact of PedsCare’s community palliative care program on the quality of life of patients and on hospital use and cost.	Medline/ PubMed

Data characterization

Four articles included in the sample were published in 2014^{10,18,19,21}, two in 2015^{13,17}, five in 2016^{15,16,20,22,23}, two in 2017^{12,14} and one in 2018¹¹. All studies were produced outside Brazil. Six of them were published in *Journal of Palliative Medicine*^{10,14,15,17,20,21}, two in *Pediatric Clinics of North America*^{18,19}, two in *BMC Palliative Care*^{11,23} and the others in *Palliative Medicine*¹², *Annali dell’Istituto Superiore di Sanità*²², *Journal of Pain and Symptom Management*¹⁶ and *Pediatrics*¹³.

As for the method, one article was a literature review²³. The qualitative design was observed in two studies, with interviews¹² or questionnaires¹⁰. Another nine studies^{11,13-16,18,19,21,22} had a quantitative approach, with a predominance of cohort studies. One study¹⁷ had a qualitative (by interview) and quantitative (by cost analysis) approach, and another was of descriptive nature²⁰.

The researched literature presented factors that stood out and will be discussed individually: the effectiveness of palliative care in hospitals; the decrease in hospital costs with the implementation of this type of assistance; the importance of interdisciplinary teams; educational needs of health professionals; and the impact on the quality of life of patients and family members.

Discussion

Effectiveness of palliative care

Herbert and collaborators¹⁰ deal with the implementation of PPC in the state of Queensland,

Australia, where this assistance is defined as an advisory and interdisciplinary service that expands care beyond the hospital, regardless of the diagnosis and the place where the child lives, via home visits, videoconference or telehealth. Patient and family members are assisted from the referral to service and diagnosis, continuing even after hospital discharge. In addition to providing consultation services for hospitalized children and offering specialized outpatient clinics in hospitals, the state also provides direct assistance with other community services.

Although the study addresses difficulties in proving the service’s efficacy and measuring the patient’s individual experience, the testimonies presented by family members and medical staffs show a positive view of palliative care. The reports consider the service valuable and effective, capable of meeting the community’s needs. The coordination of care and the promotion of the quality of life of patients and family members stand out, as the service is provided beyond the hospital environment¹⁰.

Verberne and collaborators¹¹, in turn, evaluated primary, secondary and tertiary care professionals’ perception of the palliative care team. This perception motivates professionals to collaborate with PPC, which does not replace regular clinical care, but coordinates the healthcare provided to children and families. The objective is to provide care based on trust, sharing information and the same goals¹¹.

In another study, evaluating the perception of patients’ parents, Verberne and collaborators¹² show that families have limited expectations regarding palliative assistance, and many parents find it difficult to accept their child’s

need for palliative care. But the tendency is for health professionals to gradually win the trust of the family and have their work appreciated. In this regard, the following aspects should be emphasized: continuity and coordination of healthcare, the establishment of a contact point, practical support, and a sensitive and reliable attitude. Home visits stand out and, as an improvement, parents suggest early clarifications about the team's work¹².

Considering these aspects, it is clear that palliative assistance allows a transversal healthcare, based on the principles of humanization and interdisciplinary hospital care, which govern health services.

Decrease in hospital costs

Smith and collaborators¹³ observed that the financial costs of hospitalization of children who received palliative care differ from those of children who did not receive it. The authors acknowledge that this is a very complex interrelation, but the findings suggest lower costs in cases in which these services were implemented. The length of stay was also shorter, showing the importance of pre-hospital care and prioritizing quality of life. In addition, palliative care increases the satisfaction of family members. The main limitations of the study are the inclusion of only high-cost patients and the use of administrative data from only one institution¹³.

Ananth and collaborators¹⁴ also showed that patients with serious illnesses who received palliative assistance had fewer hospital admissions and visited the emergency less often. Despite the tendency of more admissions to the intensive care unit after the start of palliative care, in the hospital in question the costs remained stable, possibly due to reductions in the use of hospital resources, even though mechanical ventilation and technological assistance were used to the same extent¹⁴.

There may be subtle changes in the use of resources, such as the reduction in surgical approaches observed by Ananth and collaborators¹⁴. However, for terminally ill patients, palliative care may not substantially change hospital use – a finding also reported by Smith and collaborators¹³ and Conte and collaborators¹⁵. Although the exact mechanisms of decreased hospital use require further investigation, PPC facilitates the reallocation of hospital care to the outpatient level, with early

conversations about care planning, including care staff, patient and family members.

In their research, Gans and collaborators¹⁶ presented the California PPC program, which offers home support, reducing costs and hospital admissions via community care. Savings of US\$3,331 per patient were estimated, in addition to a reduction of almost 50% in the average monthly hospitalizations. This important result was possible by the decrease in the frequency and duration of hospitalizations, with a relatively lower increase in outpatient costs. The mean duration of hospital stay shifted from 16.7 days to 6.5 days after enrollment in the palliative care program¹⁶.

Considering the few studies addressing costs reduction resulting from palliative care and the difficulty in analyzing the hospital's financial information, it is clear that the theme still requires further investigation

Importance of the interdisciplinary team

In the study by Jamorabo, Belani and Martin¹⁷, complex chronic conditions are identified as the main cause of death in children aged 1 to 17 years. Perinatal conditions and genetic and congenital abnormalities can affect several organs and produce other comorbidities. The diversity of these conditions reinforces the need for an interdisciplinary approach, helping families deal with possible complications and to adapt the home appropriately¹⁷.

The study also showed that most deaths occur in emergency units or at home, while a small number in palliative care institutions, which reflects the scarcity of this type of service¹⁷. However, the insufficient documentation to clarify PPC offer and the types of intervention can be pointed out as a limitation of this cohort study that started from inferences based on death certificates¹⁷.

An important characteristic of palliative care teams is that different members can take the lead, depending on the family's goals and needs of a given moment. Ogelby and Goldstein¹⁸ showed the flexible nature of these medical teams, which differ from the traditional model, in which doctors are at the top of the hierarchy, centralizing decisions. Interdisciplinary care encourages continuous communication among staff members, to reduce the family's burden of having to coordinate care and give information to several professionals. With a clearly unified approach, deliberations are more likely to be resolved by mutual agreement,

and delicate decision-making tends to not be hampered by the opinion of a caregiver who are not in tune with the rest of the team¹⁸.

Moore and Sheetz¹⁹ point out that, in palliative care consultations, the purpose is more often focused on managing symptoms, facilitating communication, making decisions, assisting the coordination of care and transition to home, and discussing non-resuscitation orders. The authors reinforce that an interdisciplinary team must provide care for children and their families, and that it is necessary to integrate different levels of healthcare (primary, secondary and tertiary)¹⁹.

Hospitals should organize palliative care staffs with the right members, without delaying their formation in the expectation of better resources. As Keele, Keenan and Bratton²⁰ state, institutions should be encouraged to start palliative care with the means available, hiring the necessary professionals – which may even increase the number of referrals²⁰.

Frizzola and Miller²¹ discuss the implementation of palliative care in a children's hospital, operating with a demand higher than the expected since the first year. Fast acceptance was credited to good planning, hospital leadership and the institution's strong clinical, administrative and financial support. There was also a great educational effort prior to the program, promoting a cultural change that favored the reception of palliative care in pediatric hospitals. The scenario contrasts with the period of initial stagnation predicted by the literature and mentioned by the authors themselves²¹.

Education of professionals

Benini and collaborators²² indicate that the lack of training in this type of assistance in academic curricula is a major challenge to form palliative care teams. This depends on the availability of health professionals with specific knowledge and experience. However, in general, the knowledge of professionals in this area is incomplete or inadequate, preventing a qualified and equitable response to the population's needs²².

Besides knowledge and clinical experience, the members should have organizational, interpersonal, and communication skills to deal with ethical dilemmas²². The absence of these skills impairs the relationship between doctors and patients' families, between professionals with different specializations, medical team members, and even between patients

and their families. Thus, the lack of properly trained professionals is the main cause of the limited or ineffective response of children to palliative assistance, even affecting the credibility of this type of care²².

Quality of life of patients and their families

Benini and collaborators²² also address the consequences of diagnosing an incurable disease in a child. There is great difficulty in dealing with the patient's needs, family's suffering and the burden of care²², and the impact of the diagnosis affects the quality of life of those involved, whose routine is severely modified by long-term treatment in a hospital setting. Special adaptations are necessary – including those aimed at the patient's school activity and the caregivers' professional activity –, which often implies the discontinuation of the projects of all those involved. Parents often experience intense feelings – helplessness, frustration, fear and anxiety – which can interfere with their decision-making ability²².

The work of Benini and collaborators²² suggests that reluctance to give up is a determining factor in the healthcare chosen by parents for their children. In this context, not accepting the impossibility of cure and the belief that palliative care is equivalent to giving up are the most critical issues²². Honest and detailed communication is essential to help family members accept the child's prognosis and prepare them for the patient's present and future needs. Parents must be informed that palliative assistance is considered the most appropriate way to help children with serious illnesses achieve the best possible quality of life and to protect their dignity²².

Final considerations

End-of-life care can provide transversal assistance at different levels, if health professionals are prepared to act in an interdisciplinary way, supporting family members and improving the patient's quality of life by ensuring more autonomy in the health-disease process. Further studies with Brazilian experiences and shared difficulties should be conducted to improve services with similar realities. There is also a need for research that address the child's perspective on the

various issues related to quality of life and illness, to improve healthcare.

This study sought to take a step in this direction by providing information for implementing palliative

care services in the country, which could humanize and integrate healthcare and, therefore, should be recognized as a specialized and crucial service for pediatric patients with incurable diseases.

Article based on the final paper of the medical residency program in general pediatrics at Hospital Albert Sabin, Fortaleza, Ceará, Brazil.

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Participation of the authors

The authors participated equally in the writing of the article.


Amanda Andrade Aguiar de Pinho

 0000-0003-2885-5070


Isabel Regiane Cardoso do Nascimento

 0000-0002-5665-0577

Igor Weyber da Silva Ramos

 0000-0002-2788-4219

Vanilla Oliveira Alencar

 0000-0002-4269-7147



Received: 3.12.2019

Revised: 10. 1.2020

Approved: 10. 2.2020