Review

Pediatric Palliative Care in children and young people with non-oncological diseases: a scoping review

Marina Maffeo[1], **Irene Sartorio**[1], **Maria Elena Fiani**[1], **Biagio Nicolosi**[2], **Daniele Ciofi**[3]

[1] *Pediatric Intensive Care Unit, Meyer Children's Hospital IRCCS, Florence, Italy*
[2] *Wound Clinical Specialist, Complex Injury and Burn Center, Department of Health Professions, Meyer Children's Hospital IRCCS, Florence, Italy*
[3] *Research Development Manager, Department of Health Professions, Meyer Health Campus, Florence· Italy*

Citation: Maffeo M., Sartorio I., Fiani M.E., Nicolosi B., Ciofi D. "Pediatric palliative care in children and young people with non-oncological diseases: a scoping review" (2024) *infermieristica journal* 3(1): 15-23. DOI: 10.36253/if-2542

Received: January 08, 2024

Revised: March 1, 2024

Just accepted online: March 12, 2024

Published: March 31, 2024

Competing Interests: The Author(s) declare(s) no conflict of interest.

Abstract

Background: Pediatric Palliative Care (CPP) is defined as active and holistic care of the child's body, mind and spirit, actively supporting the centrality and role of the family. They have as their primary objective the improvement of the quality of life of children and their families, supporting them in treatment choices. CPPs should be planned at the time of diagnosis, in order to be able to initiate the patient and family early on to a type of care that responds to the multiple needs that the situation entails, without precluding concomitant curative therapy. In fact, it has been shown that they are all the more effective the earlier they are integrated into the child's treatment plan. However, despite the international recognition of CPPs as an integral part of the right to health, implementation and effective access to such services remain limited in many contexts, including Italy. challenges to CPPs integration are multiple and include the complexity of clinical conditions, lack of training of healthcare professionals, regulatory and regional politicy issues, and socio-cultural barriers.
Aim: The primary aim of this scoping review is to investigate the current landscape of PPCs for children and young people with life-limiting non-oncological conditions in Italy and worldwide in terms of benefits, eligibility, impact on the family and the barriers associated with treatment.
Materials and method: A scoping review was performed between September 2023 and January 2024 following the PRISMA guidelines using the keywords "pediatric palliative care" AND "chronic disease/barrier/eligibility/parents.

Results: Ten full-text articles met the inclusion criteria. The major studies were quantitative, cross sectional. The finding demonstrates that early inclusion of complex chronic non-oncological patients in palliative care programs leads to greater patient and family satisfaction, reducing emotional burden and improving communication and treatment planning. Parents experience stress and financial difficulties. Parent psychological distress was associated with parent-reported patient symptoms and financial difficulty. Major challenges include the lack of support networks and training in palliative care, along with legal and economic issues.

Conclusions: While there is growing recognition of the importance of CPP, further efforts are needed to address challenges in accessing and integrating services, as well as meeting the needs of patients, families and healthcare professionals working in this field. Improving knowledge and awareness about CPP can help overcome barriers to accessing services and improve the quality of care provided to pediatric patients and their families.

Keywords: Chronic Disease, Pediatric Palliative Care, Barrier, Eligibility, Parents, Pediatrics.

Introduction

Pediatric palliative care (PPC) is defined as active and holistic care of the child's body, mind and spirit, actively supporting the centrality and role of the family[1]. They have as their primary goal the improvement of the quality of life of children and their families, supporting them in their choices of care[2,3]. In 2020, the World Health Organization (WHO) recognizes palliative care as part of the right to health[4]. PPC should be provided from the time of diagnosis to enable early initiation of care for the patient and family. This approach aims to meet the multiple needs arising from the situation early, while ensuring continuity of curative care[5]. CPP is not terminality care (referring to the period strictly related to the event of death), although it includes it, but it provides early care at the time of incurability: it begins at the time of diagnosis, including prenatal, and continues throughout the history of the disease, until after death, with follow-up and family counseling for bereavement management[6,7]. PPC programs have been found to be most effective when they are integrated into the child's treatment plan as early as possible. They differ in many areas from the adult patient's palliative care: they must modulate to the biological, psycho-relational, clinical, social, ethical and spiritual peculiarities of the pediatric patient, who is taken care of for a longer period of time. Compared with adults with palliative care needs, the group of children is significantly smaller but at the same time highly heterogeneous[8]. Palliative care has three main benefits for patients and families: it improves the child's quality of life, relieves symptoms, and supports family decisions. When palliative care is integrated into the child's treatment, the child is more likely to receive care in line with goals[9]. They can also provide so-called "respite care" to enable family members to take a break from their role as caregivers[10]. Indeed, it is also necessary to consider the impact this type of illness has on the lives of parents, who often experience high levels of psychological stress, anxiety and depression[11]. In fact, in the study by Boyden et al. (2022)[12], the association between parents' psychological distress, children's symptoms and economic difficulties was analyzed with the aim of determining the link between these factors. The increasing incidence of children with chronic diseases and/or severe disabilities is leading to a significant increase in pediatric patients who could benefit from inclusion in PPC programs. This approach aims to ensure that patients and their families have the highest possible quality of life until the end of their illness[13]. The integration of PPC services faces several challenges, including the complexity of clinical conditions, the lack of preparedness of healthcare professionals, and regulatory and policy issues[14]. Parents often have mixed feelings about the need for PPCs, sometimes interpreting them as a sign of surrender. Health professionals' training on the topic is lacking, and early implementation of PPCs is hampered by prognostic uncertainties, emotional distress of health and family staff, and a shortage of specialized teams, so access is still limited to PPC services in many industrialized countries, including Europe[15]. In Italy, despite the Law 38/2010 recognizes PPC as a child's right, it is estimated that only less than 15 percent of child candidates actually have access to such services[16]. According to the International Children's Palliative Care Network (ICPCN), there would be at least 20 million children worldwide who, annually, could benefit from a network of palliative care services and 8 million who would need specialized PPC[17]. The determination of eligibility for pediatric palliative care is based primarily on the presence of a disease that is considered incurable, but not all incurable medical conditions necessarily require PPC intervention. In addition to the diagnosis of incurability, eligibility depends on the extent of problems faced by the child and family, considering clinical, psychological, social, organizational, spiritual, or ethical aspects and related care needs. In the pediatric settings, establishing eligibility criteria for PPCs can be problematic, requiring a thorough assessment of the child's condition and family needs[18,19]. Historically, palliative care originated to address the patient with oncologic disease, but approximately 75 percent of the diseases requiring this specific care in the pediatric setting are nononcologic in nature, while only an estimated 25 percent are oncology patients[20]. However, still very few eligible children with non-oncologic disease are included in PPC programs[21,22]. The aim of the present scoping review is to describe the current landscape of PPC for children and young people with life limiting non-oncological conditions, particularly in Italy, in terms of benefits, eligibility, impact on the family and the barrier factors.

Materials and method

A scoping review of the literature was performed. The team working on this research was composed of nurses, who identified the research question and the inclusion criteria. To carry out this review, the steps proposed by Arksey and O'Malley were followed: identification of the research question, identification of relevant studies, selection of studies, and data extraction[23]. Furthermore, the statement of preferred reporting items for systematic reviews and Meta-Analyses statement for scoping reviews (PRISMA-ScR) checklist was used to facilitate presentation and improve research quality[24].

Identification of research question

The following research question was formulated: 'What is the current landscape of PPC for children and young people with life-limiting non -oncological conditions in Italy and worldwide in terms of benefits, eligibility, impact on the family and barriers associated with treatment?'

The research question was formulated according to PEO (Table 1)[25].

P	Population	Children and young people with non-oncological life-limiting conditions
E	Exposition	Pediatric Palliative Care
O	Outcome	Any kind of outcomes

Table 1. PEO

Identification of relevant studies

The search was performed between September 2023 and February 2024 in three databases: MEDLINE/PUBMED, EMBASE, and the Cumulative Index to Nursing and Allied Health Literature (CINAHL). The keywords used for the search were chronic disease; pediatric palliative care, barrier, eligibility, parents.

The search terms were presented in various combinations to obtain the best results and ensure a comprehensive search. The Bolean operators OR, AND and NOT were used.

Selection of studies

From the articles identified by the literature search, duplicates were removed. The titles and / or abstracts were then reviewed and studies relevant to the research question were identified. The full texts of the remaining articles were read and selected according to the criteria listed in Table 2.

Inclusion criteria	Exclusion criteria
In Italian and English	Reviews, book chapters, books, congress abstracts, letters, editorials
Studies published between 2021 and 2023	Studies that are not focused on PC
Qualitative, quantitative and mixed methods studies published in scientifics journals	Studies that are focused on oncological diseases
Studies that collect variables on the structure and process of care of patients with chronic life-limiting conditions	Articles found not to be relevant or appropiate
Full text available	

Table 2. Inclusion and exclusion criteria

Data extraction

Data extraction from each article was carried out using an Excel spreadsheet that included the author and year, country, objective, methodology and technique used, cohort (patients, families and / or professionals), settings that are addressed, results and outcome.

Results

The flow chart (Figure 1) shows 785 articles retrieved, broken down as follows: 414 from MEDLINE/PUBMED; 297 from EMBASE; 74 from CINAHL. Articles that were not relevant, for search purposes, were then eliminated: by title (711 articles); by abstract (33 articles, including 4 duplicates and 5 due to absence of full text). After reading of the full text, another 31 articles were eliminated because they did not meet the inclusion criteria. A total of 10 articles were then considered and analyzed in the literature review. Their main characteristics are detailed in Table 3.

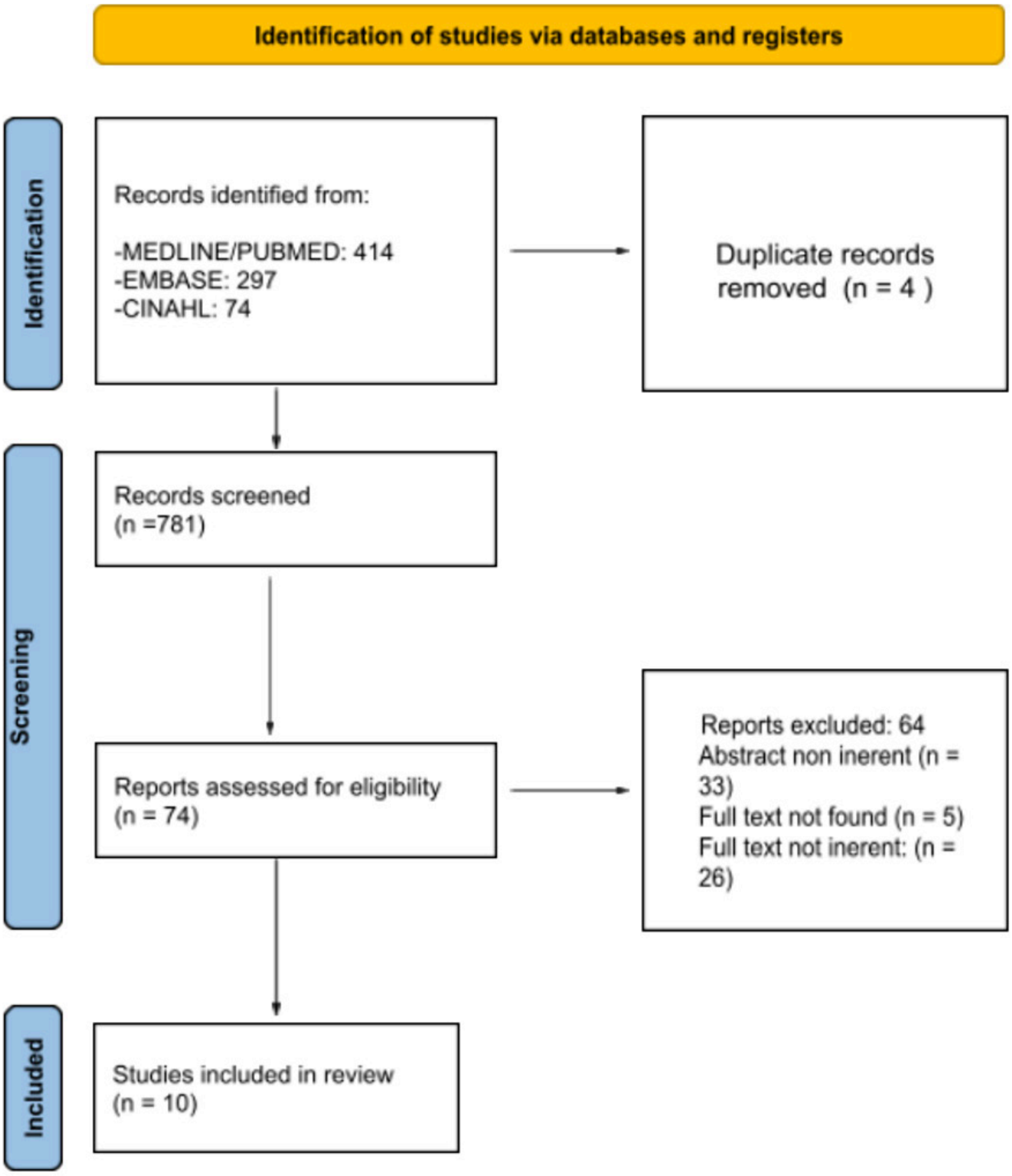

Figure 1. PRISMA Flow Chart

	Authors (year) country	Study title	Aim	Patient and setting	Study design	
1	Geithner, E.M (2023) USA	An Extra Layer of Support: Pediatric Palliative Care	To describe, benefits, and barriers of PC for patients and their families	One hospitalized patient and one patient at home	Case studies	
2	Bogetz J.F. et al. (2021) USA	Paediatric Palliative Care for Children with Severe Neurological Impairment and Their Families	To evidence that early and ongoing palliative care helps to Build a trusting relationship with the medical team and collaborate with the family to support their goals	Patient hospitalised with severe neurologic impairment (SNI)	Case study	
3	Jankovic et al. (2019) Italy	A consensus conference report on defining the eligibility criteria for pediatric palliative care in Italy	To define a standard set of criteria for establishing pediatric palliative care (PPC) eligibility	A multidisciplinary group of eight health care professionals (doctors, nurses, and psychologists) who worked from home. May 2014 to February 2016 to reach a consensus over PPC eligibility	Report	
4	Amarri et al. (2021) Italy	Children with medical complexity and paediatric palliative care: a retrospective cross-sectional survey of prevalence and needs	To investigate the prevalence of children with medical complexities eligible for a local palliative care network, including a paediatric hospice.	The survey has been conducted using children's clinical charts from 14 local centres. health authorities of a region in Italy (Emilia Romagna)	A retrospective cross-sectional survey	
5	Falsaperla R. et al. (2023) Italy	Need for palliative care from birth to infancy in pediatric patients with neurological diseases	To analyse palliative care and propose the implementation of hospital palliative care for the long-term prognosis of patients with neurological diseases	34 newborns with diseases that affect the nervous system, affecting the prognosis at the Neonatology Intensive Care Unit and the Paediatric Unit of the San Marco University Hospital in Catania, Sicily, Italy	Retrospective observational study	
6	Caggiano S. et al. (2022) Italy	Children with medical complexity and pediatric palliative care: Data by a respiratory intermediate care unit	To describe the clinical aspects and needs in children with medical complexity (CMC)	130 patients with CMC, admitted to the Respiratory Intermediate Care Unit of a tertiary referral hospital, Bambino Gesù Children's Hospital	Retrospective observational study	
7	Boyden J.Y. Et al. (2022) USA	Pediatric palliative care parents' distress, financial difficulty, and child symptom	To examine the associations among parent psychological distress, parent- reported patient symptoms and financial difficulty, seeking to determine the relative association of financial difficulty and of the patient symptoms to parent psychological distress	601 parents of 532 pediatric palliative care Patients enroled in a prospective cohort study conducted in seven US children's hospitals	Cross sectional study	
8	Lee et al. (2021) Korea	Factors Associated with Quality of Life in Children Receiving Pediatric Palliative Care	To examine the clinical and family factors associated with health-related quality of life (HRQoL) of children with life-limiting conditions (LLC)	136 paediatric patients with LLC who were enroled in the PPC services at Seoul National University Hospital in South Korea	Cross sectional study	
9	Gruneberg et al. (2021) Mexico	Challenge in the provision of paediatric palliative care in Mexico: a Cross-Sectional Web-Based-Survey	To identify the current challenges in the provision of PPC and their severity from the perspective of healthcare professionals	70 healthcare professionals from Mexico participated	Cross Sectional Study	
10	Kang et al. (2022) Korea	Nurse's Perceived Needs and Barriers Regarding Pediatric Palliative Care: A Mixed Methods Study	To describe nurses' perceived needs and barriers to pediatric palliative care (PPC)	72 nurses who voluntarily consented and participated in the study	Cross Sectional Study	

Table 3. The main characteristics of the included studies.

Results	Outcome
Palliative care can be provided at any point in an illness trajectory. It is often delivered in the home, but also in the paediatric hospital unit. Palliative care has benefits for patients and families	Early integration of palliative care into the treatment of a child has many benefits to the patient, family, and medical team, despite both present obstacles to the early implementation pediatric palliative care
Children with SNI and their families have unique needs that are well met by paediatric palliative care teams. Comprehensive palliative care for children with SNI also includes symptom management and spiritual/psychosocial support	Palliative care teams can have a large impact through the ways they are administered. they support these patients and their families psychosocially, symptomatically, spiritually, and emotionally
The consensus conference draughted a final document determining the guidelines for PPC eligibility of newborns, infants, children, and adolescents suffering from oncological or non-oncological diseases	This report provides health care providers with practical guidelines on how to define eligibility. pediatric patients for PPC
The total number of children with life-limiting conditions was 601. Neurological diseases affected 51% of the patients, followed by congenital diseases (21%) and conditions originating in the perinatal period (6%), while only 4% of the patients had a cancer diagnosis	The observed regional prevalence of complex needs is lower than that published by other European countries. There is a need to increase awareness of palliative care for children to address specific needs.
Three patients suffering from extreme prematurity, six with severe metabolic encephalopathies, eight with genetic encephalopathies, seven with neuromuscular diseases, nine with hypoxic-ischemic encephalopathy, and 1 patient with surgically treated posthemorrhagic hydrocephalus were included in the analysis	No palliative care network has been activated. It is necessary to activate a straightforward departmental unit for neurologic pediatric palliative care
The main pathologies recorded were neuromuscular, neurological, respiratory, metabolic, malformative diseases, genetic syndromes, and prematurity outcomes. Comorbidity due to respiratory, digestive, neurological, cardiac, and urological involvement was present in a high percentage of cases	The number of children and young people (CYP) living with life-limiting and life-threatening conditions is rising due to the continuous advances in clinical medicine. The analyzed population was significantly heterogeneous. Patients' needs have a significant impact on the family unit
Most parents were moderately to severely distressed. distressed (52%) or severely distressed (17%) and experienced some degree of financial difficulty (65%)	Parental psychological distress was associated with a patient symptoms and financial difficulty.
Most children with CLL have poor HRQoL at the time of enrollment in PRA services, with significant variations in total HRQoL scores according to diagnostic categories. Patients with non-malignant conditions showed significantly lower HRQoL scores than patients with malignancy	Lower HRQoL is associated with greater caregiver depressive symptoms. An optimised intervention in palliative care for children with nonmalignant pathologies and a family-centred intervention to address the psychosocial problems of caregivers are needed.
The three most severe barriers reported were: (1) Few outpatient / domestic support teams and/or networks of out-of-hospital/domestic support; (2) Lack of training centers and continuing medical/paramedical education in the PPC; and (3) Lack of legal, labour and economic protection for parents	Have identified several barriers to successful palliative care (PC) provision for children: lack of awareness and commitment, lack of personal and financial support, legal factors, and working conditions. The need to change and improve care exists at the level of the policy level, the health professional and the public societal level.
The needs for PPC were divided into 4 categories "children and adolescents," "families," "PPC management system," and "community-based PPC." Meanwhile, the barriers to PPC were divided into 3 categories "healthcare delivery system," "healthcare provider," and "client"	For stable establishment of PPC, the priority should be given to improving perceptions of PPC, establishing an appropriate system, and training professional care providers

Of the 10 selected articles, four are from Italy, three from the USA, one from Mexico, and two from Korea. We grouped the studies according to the investigated topic. The studies by Geithner et al. 9 and Bogetz et al., explore the current landscape of pediatric palliative care, focusing on benefits, eligibility, family impact, awareness, and barriers[11]. Geithner's study describes two case studies. The first about a child suffered myelomeningocele, with terrible abdominal pain not relieved by previous prescribed medications. After the intervention of the palliative care team, Jose was brought back to the ward and started hydromorphone therapy via PCA (patient demand analgesia pump), with the intention of later starting methadone therapy for long-term pain relief at home. The second case studies Chris, a 12-year-old boy with a degenerative neuromuscular disease, who receives support from an outpatient palliative care team. When Chris experiences new symptoms due to his condition, the palliative care team collaborates with other providers to implement interventions, pharmacological and otherwise, to improve his comfort and quality of life. Both studies described the benefits of palliative care for patients and their families, the challenges in early integration of palliative care, and the importance of nurse involvement in paediatric palliative care advocacy.

Studies by Jankovic et al. and Amarri et al. define standard criteria to determine eligibility for pediatric palliative care (PPC) for infants, children, and adolescents, considering the specific clinical characteristics of these patients that make adult PPC protocols inappropriate[13,26]. In Jankovic's study, the consensus conference method was used; a multidisciplinary group of eight healthcare professionals worked to reach a consensus on the eligibility criteria. These experts drafted a document that was subsequently reviewed by a multidisciplinary jury and then by an extended team of experts. The result was a final document establishing PPC eligibility guidelines for infants, children, and adolescents with oncologic and non-oncologic diseases. Amarri's study et al. examines the prevalence of children with complex medical conditions (CMC) eligible for PPC in a local palliative care network, including a paediatric hospice. Through a survey of children's medical records from 14 local health authorities in the Emilia Romagna region, Italy, it was found a total of 601 children with life-limiting conditions, with a mean age of 7.4 years, with a prevalence of 8.4/10,000 residents <19 years. Neurological diseases affect 51% of patients, followed by congenital diseases (21%) and diseases originating in the perinatal period (6%), while only 4% have a cancer diagnosis. Falsaperla et al. examines the application of palliative care in neurological patients from birth to early childhood, with the aim of analysing the protocols used, describing the palliative pathway in the clinical setting, and proposing the implementation of hospital-based palliative care to prolong the prognosis of patients with neurological diseases [27]. Through a monocentric retrospective observational study, 34 infants with prognosis-compromising diseases of the nervous system were examined. The study conducted by Caggiano et al. describes a population of children with complex medical conditions (CMC) attending the Intermediate Respiratory Care Unit of a tertiary referral hospital for southern and central Italy. Of the 275 children admitted, 130 CMC were included. A significant need for specialized pediatric palliative car was found, especially to manage respiratory symptoms[28].

Studies by other authors focused on family aspects. Boyden et al. examines the associations between parents' psychological distress, symptoms reported by patients' parents, and families' financial difficulties, seeking to determine the relative association of patients' financial difficulties and symptoms with parents' psychological distress. Most parents reported moderate to severe psychological distress (52%) or severe psychological distress (17%) and experienced some degree of financial difficulty (65%)[12]. The study by Lee et al. examines the clinical and family factors associated with health-related quality of life (HRQoL) of Koreans children with life-limiting conditions (CLL) receiving paediatric palliative care. Most children with CLL have poor HRQoL at the time of entry into PPC services, with significant variations in total HRQoL scores according to diagnostic categories. Patients with non-malignant conditions showed significantly lower HRQoL scores than patients with malignancy. Lower HRQoL scores were associated with greater caregiver depressive symptoms. Physical health summary scores were significantly associated with caregiver diagnostic categories and depressive symptoms. Psychosocial health summary scores were significantly associated with diagnostic categories, patient location, and caregiver depressive symptoms[29].

Other author are focused on barriers and challenges in the provision of PPC from the prospective of healthcare professionals. A cross-sectional descriptive web survey conducted by Gruneberg et al. examines current challenges in the provision of PPC in Mexico among health professionals caring for children in need of palliative care. The three main barriers reported were the lack of outpatient teams and support networks, the absence of continuing medical/paramedical education and training centres in PPC, and the lack of legal, labour, and economic protection for parents who have to stop work to be with their children. The participants emphasised the importance of increased awareness and knowledge of PPC for all, particularly highlighting the need for better training of healthcare professionals[30]. The study by Kang et al., describe nurses' perceived needs and barriers in PPC. An online survey was conducted among nurses who participated in the End-of-Life Nursing Education Consortium Pediatric Palliative Care (ELNEC-PPC) educator training program. Authors stated that for an effective establishment of PPC, the priority should be given to improving perceptions of PPC, establishing an appropriate system, and training professional care providers[31].

Discussion

The objective of this scoping review is to highlight the importance of early palliative care team involvement in chronic life limiting diseases, describe eligibility criteria, examine family participation, children's needs and aspects, and identify current challenges and barriers in the delivery of PPCs providers. From the literature landscape presented, several themes and areas of interest emerge in the context of pediatric palliative care. These researches offer a broad and nuanced view of the challenges, benefits, eligibility guidelines, family needs, and needs of healthcare professionals in the field of PPC. The importance of CPP in improving the quality of life of paediatric patients with life-limiting chronic diseases and their families has been emphasised by several studies[9,11]. Nurses play a key role in identifying patients who might benefit from palliative care and providing essential emotional and clinical support. However, there are barriers to the early implementation of palliative care, such as prognostic uncertainty and emotional distress of health care providers. Better education and awareness of the importance of paediatric palliative care can improve access and optimise outcomes for children with life-limiting or life-threatening diseases and their families. The eligibility guidelines for PPC are an important step toward ensuring that children and adolescents with life-limiting conditions receive appropriate palliative care. These guidelines take into account the specific clinical characteristics of paediatric patients, which may differ significantly from those of adults[13,26]. Numerous studies examining the eligibility of paediatric palliative care for children with chronic life-limiting illnesses. These studies often focus on defining eligibility criteria, identifying eligible patients, and optimising the quality of care provided. Regarding the clinical aspects and needs in children with medical complexity, some studies focused on pediatric patients with neurological and respiratory problems. Both studies highlight the complexity and importance and the need to provide integrated and specialised care to improve the quality of life of patients and their families[27,28]. Regarding family aspect, was highlighted the importance of family involvement. Families play a key role in pediatric palliative care programs by providing emotional support to the sick child, collaborating with the medical team in care planning, participating in medical decisions, providing home care and support during the bereavement period. Family involvement and support are crucial to ensure that the child receives high-quality care, while the family is supported throughout the care journey[12,29]. However, it was shown that parental psychological distress was associated with parent-reported patient symptoms and financial difficulty. The needs have a significant impact on the family unit. The strong association between caregiver depressive symptoms and patients' HRQoL suggests that caregivers' emotional state may directly influence the perceived well-being and quality of life of children with CLL, highligthing the importance of support and assistance to caregivers as well. However, significant challenges also arise in the early integration of PPC and access to such services. Barriers to accessing PPC were identified, including the lack of support networks outside the hospital, the absence of PPC training centers, and the lack of legal and economic protection for parents who have to stop work to care for their children[30]. Kang et al. divided pediatric palliative care (PPC) needs and related barriers into specific categories to better understand and address the challenges of providing palliative care to children and adolescents with life-limiting illnesses and their families[31]. These categories include challenges related to the health care system, such as availability of services and resources; health care provider issues, such as staff training and competence; and challenges faced by clients, such as limited access to services or financial barriers. In summary for a stable establishment of PPCs, priority should be given to improving the perception of PPCs, creating an appropriate system, and training professionals.

Conclusions

While there is growing recognition of the importance of CPP, more efforts are needed to address challenges in accessing and integrating services, as well as meeting the needs of patients, families, and healthcare professionals working in this field. Improving knowledge and awareness of CPP can help overcome barriers to accessing services and improve the quality of care provided to paediatric patients and their families. It is a need to improve the training of health professionals to ensure that they have the skills needed to provide high-quality palliative care to children and their families. The specific needs of children with nononcological or rare diseases may be overlooked in the existing literature. It is important to conduct further research to better understand these needs and develop specific treatment approaches. Addressing these gaps in the literature is essential to improve the quality of pediatric palliative care and ensure that every child has access to compassionate care.

References

1. World Health Organization. Cancer pain relief and palliative care in children.1998. Accessed September 2, 2021. https://apps.who.int/iris/handle/10665/42001
2. Scarani R. Le cure palliative pediatriche nel mondo: Analisi della letteratura. La Rivista Italiana di Cure Palliative. 2021;23(1):69-74.
3. Mitchell S, Morris A, Bennett K, Sajid L, Dale J. Specialist paediatric palliative care services: what are the benefits? Arch Dis Child. 2017 Oct;102(10):923-929.
4. World Health Organization. Palliative care. 2020. https://www.who.int/news-room/fact-sheets/detail/palliative-care
5. Alleva E, Benini F, De Santi A, Geraci A. and Orzalesi M. Cure palliative pediatriche in Italia: stato dell'arte e criticità. Epidemiologia e Sanità Pubblica, 2017; 17(6): 1–39.
6. O'Shea ER, Bennett Kanarek R. Understanding pediatric palliative care: what it is and what it should be. J Pediatr Oncol Nurs. 2013 Jan-Feb;30(1):34-44.
7. National Summary of Hospice Care - Peer Reports 2009. www.nhpco.org/nds
8. Bergsträsser E. Pädiatrische Palliative Care: was ist bei Kindern anders als bei Erwachsenen? Paediatric Palliative Care: What is different in children compared to adults? Ther Umsch. 2018 Jul;75(2):101-104.
9. Geithner E.M. An extra layer of support: Pediatric palliative care. Pediatric
10. Nursing, 2023; 49(6), 269-274, 288.
11. Rao SR, Gupta M, Salins N. The Concept of Respite in Palliative Care: Definitions and Discussions. Curr Oncol Rep. 2021 Feb 9;23(2):25.
12. Bogetz JF, Lemmon ME. Pediatric Palliative Care for Children With Severe Neurological Impairment and Their Families. J Pain Symptom Manage. 2021 Sep;62(3):662-667.
13. Boyden JY, Hill DL, Nye RT, Bona K, Johnston EE, Hinds P, Friebert S, Kang TI, Hays R, Hall M, Wolfe J, Feudtner C; PPCRN SHARE Project Group. Pediatric Palliative Care Parents' Distress, Financial Difficulty, and Child Symptoms. J Pain Symptom Manage. 2022 Feb;63(2):271-282.
14. Jankovic M, De Zen L, Pellegatta F, Lazzarin P, Bertolotti M, Manfredini L, Aprea A, Memo L, Del Vecchio A, Agostiniani R, Benini F. A consensus conference report on defining the eligibility criteria for pediatric palliative care in Italy. Ital J Pediatr. 2019 Jul 22;45(1):89.
15. Spitella E, Biagioli V, Tiozzo E, Mustari M, Gawronski O, Salata M. and Dall'Oglio I. Cure palliative pediatriche nei bambini e giovani affetti da patologie non oncologiche: una revisione narrativa. L'infermiere, 2021; 58(6), e117–e129.
16. Neuburg L. Early Initiation of Pediatric Palliative Care. J Pediatr Health Care. 2021 Jan-Feb;35(1):114-119.
17. Benini F. Conferenza di consenso - le cure palliative pediatriche: dalla diagnosi di inguaribilità al lutto 29/04/2016.
18. Friedrichsdorf SJ, Bruera E. Delivering Pediatric Palliative Care: From Denial, Palliphobia, Pallilalia to Palliactive. Children (Basel). 2018 Aug 31;5(9):120.
19. Pellegatta F, De Zen L, Lazzarin P, Jankovic M, Bertolotti M, Manfredini L, Aprea A, Benini F. La definizione della eleggibilità alle cure palliative pediatriche Medico e Bambino 2016;35(9):573-578
20. Benini F, Manfredini L, Lefebvre D'Ovidio S, Spizzichino M. Progetto bambino: Cure palliative rivolte al bambino con malattia inguaribile. La Rivista Italiana di Cure Palliative, 2011; 13(4), 27–33.
21. Harrop E, Edwards C. How and when to refer a child for specialist paediatric palliative care. Arch Dis Child Educ Pract Ed. 2013 Dec;98(6):202-8.
22. Benini F, Ferrante A, Facchin P. Le cure palliative rivolte ai bambini, 2007, Volume. 14, N. 5, Pag. 213-217.
23. Benini F, Cauzzo C, Congedi S, Da Dalt L, Cogo P, Biscaglia L, Giacomelli L. Training in pediatric palliative care in Italy: still much to do. Ann Ist Super Sanità. 2019; 55:240–5
24. Arksey H, O'Malley, L. Scoping Studies: Towards a Methodological Framework. Int. J. Soc. Res. Methodol. 2005, 8, 19–32.
25. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. Ann Intern Med. 2018 Oct 2;169(7):467-473.
26. Polit DF, Beck tc. Fondamenti di Ricerca Infermieristica. 2° Edition. Milan: Mc-Graw-Hill; 2014.
27. Amarri S, Ottaviani A, Campagna A, De Panfilis L; Emilia Romagna paediatric palliative care working group. Children with medical complexity and paediatric palliative care: a retrospective cross-sectional survey of prevalence and needs. Ital J Pediatr. 2021 May 12;47(1):110.
28. Falsaperla R, Marino S, Moscheo C, Tardino LG, Marino SD, Sciuto C, Pavone P, Vitaliti G, Sullo F, Ruggieri M. Need for palliative care from birth to infancy in pediatric patients with neurological diseases. Clin Exp Pediatr. 2023 Aug;66(8):350-356.
29. Caggiano S, Pavone M, Cherchi C, Paglietti MG, Schiavino A, Petreschi F, Chiarini Testa MB, Cutrera R. Children with medical complexity and pediatric palliative care: Data by a respiratory intermediate care unit. Pediatr Pulmonol. 2023 Mar;58(3):918-926.
30. Lee J, Kim MS, Kim CH, Moon YJ, Choi YH. Factors Associated With Quality of Life in Children Receiving

Pediatric Palliative Care. J Pain Symptom Manage. 2022 Mar;63(3):395-403.

31. Grüneberg ES, Ramos-Guerrero J, Pastrana T. Challenges in the Provision of Pediatric Palliative Care in Mexico: A Cross-Sectional Web-Based Survey. J Palliat Care. 2024 Jan;39(1):58-67.
32. Kang KA, Yu S, Kim CH, Lee MN, Kim S, Kwon SH, Kim S, Kim HS, Park MH, Choi SE. Nurses' Perceived Needs and Barriers Regarding Pediatric Palliative Care: A Mixed-Methods Study. J Hosp Palliat Care. 2022 Jun 1;25(2):85-97.