



Nursing Perspective of Providing Palliative Care to the Children—A Narrative Review

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J Health Allied Sci^{NU}

Abstract

Introduction Palliative care of children (PCC) is a philosophical and a structured approach to providing tailored care to children with life-threatening diseases. Understanding the role of nurses and empowering them to take up the role of palliative care nurse are imperative to strengthen these services and make the palliative care services more accessible to the patients.

Method The literature search was done in two database, PubMed and Scopus, using keyword and Medical Subject Headings (MeSH) terms such as children, palliative care, end of life, hospice, bereavement, and nursing. Records were screened by authors and relevant articles were included in the review.

Discussion PCC should start with the diagnosis of the illness continue through all the phases of illness. Bereavement support to the family is also a part of palliative care. Nurses are in a key position to play important role in the PCC team. Nurses play various roles such as direct care provider, communicator, patient advocate, respite nurse, and counselor.

Conclusion PCC is aimed to improve the quality of life of the child and family. It is crucial to achieving universal health coverage. Role of nurse is vital in providing PCC.

Keywords

- ▶ bereavement care
- ▶ children
- ▶ end of life care
- ▶ nursing
- ▶ palliative care

Introduction

Pallium, which means cloak in Latin, is where the word “palliative” originates. Palliative care seeks to minimize discomfort and alleviate the patient’s suffering even when curative therapies are no longer an option. Palliative care of children (PCC) is a philosophy and a structured approach for providing tailored care to children suffering from life-threatening diseases and their family members. PCC strives to improve the “quality of life” of child/family, avoid or lessen pain, improve functioning, and offer opportunities for personal and spiritual development.”¹ “Palliative Care of children is the

active total care of the child’s body, mind and spirit, and also involves giving support to the family (WHO 1998).”² It starts with the diagnosis of illness and continues throughout the illness, irrespective of the prognosis. Even after the patient’s death bereavement support is extended to the family.

Palliative care should be integrated into the care of any child suffering from a condition that can potentially shorten the patient’s life, such as cancers and congenital heart disease (life-limiting conditions) or suffering from a severe condition that could cause death (life-threatening conditions). Patients with the following conditions can be benefited from palliative care.³

DOI <https://doi.org/10.1055/s-0043-1769081>.
ISSN 2582-4287.

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- Diseases such as cancer and congenital heart diseases.
- Chronic progressive diseases
- Progressive diseases which are not curable
- Nonprogressive irreversible conditions with high chances of disease-related complications.

Palliative care is delivered by a multidisciplinary team including pediatrician, palliative care physician, medical social service officer, physiotherapist, pharmacists, nursing officers, dietician, and psychologist. However, it can be provided in a resource-limited setting also. Nurses are essential part of PCC team.⁴ They are positioned to assess and identify symptoms at first instance, deliver therapeutic care, coordinate with the healthcare team, effectively communicate, and serve as a patient advocate. Understanding the role of nurses and empowering them to take up the role of PC nurse is imperative to strengthening these services and making them more accessible. Nursing interventions are emerging through research. Researchers are exploring new ways to help the patients and their family members. It is the need of hour to synthesize the evidence-based nursing interventions relevant to pediatric palliative care. Therefore, this review was undertaken with the objective to find out emerging role of nurses in palliative care services for children affected with life-limiting/life-threatening illnesses and its implications for nursing sciences.

Methods

The articles were searched in two databases, PubMed and Scopus, using keywords and Medical Subject Headings (MeSH) terms combined with Boolean operators 1. (“Palliative care” OR “hospice care” OR “End of life care” OR “Bereavement Care”) 2. (Child OR Children OR Pediatric* OR Pediatric*) 3. (“Nursing care OR “Nursing perspective” OR “Role of Nurse” OR “Nursing Responsibility”) 4. (1 AND 2 AND 3). Only the articles published between Jan 2011 and Feb 2023 were included. Following criteria were used to select studies.

Inclusion Criteria

- Original research and review articles reported role of nurses in providing palliative care services to the children
- Published in English language
- Full text retrievable were included.

Exclusion Criteria

- Editorial, protocols, conference reports, and abstracts.
- Articles dealing with perinatal and neonatal palliative care.

Results

A total of 503 article retrieved on searching both the databases. Search results were exported to Zotero, and duplicates were removed. Two authors (US and RG) screened the title

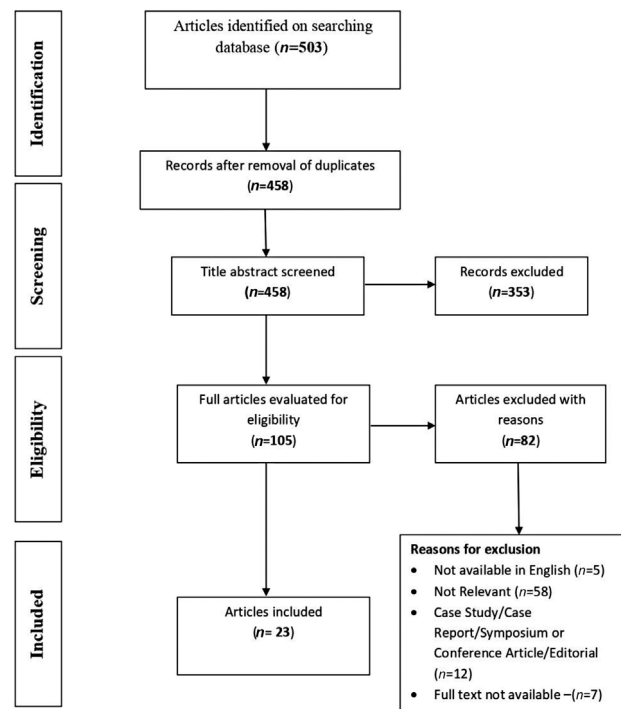


Fig. 1 Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) chart.

and abstract independently. A total of 105 articles were shortlisted for full-text review based on the inclusion and exclusion criteria. Full texts for the articles were retrieved, and three authors (US, JS, and RG) evaluated the articles for relevance to the review. A total of 23 relevant articles were included in the final review (→ Fig. 1).

Discussion

The findings of selected articles were synthesized to understand the nursing perspective, the role of nurses in the children's palliative care and its implications for nursing sciences

Conceptual Understating of Palliative Care

For many decades, the meaning of the term palliative care has been negatively connoted with hospice or end-of-life care.⁵ Patients are offered palliative care services relatively late in the course of illness, even though it is now universally acknowledged as an essential component of effective care of children suffering from life-limiting diseases. Palliative care services were sought when curative options were exhausted or very limited.^{6,7}

But palliative care should start concurrently with the disease-modifying treatment and continue regardless of the intent of treatment and stage of the disease. If the disease progresses, the palliative care takes over and continues till the patient's death and beyond by providing bereavement support to the family. Implementing a concurrent care model requires a unified commitment to objectives focused on treatment and life-prolongation strategies and an equal

dedication to symptom treatment and pain reduction.^{2,8} The nurses can play important role in every phase of palliative care.

Goals of Palliative Care of Children

Goals of PPC are to alleviate suffering and optimize the quality of life of children affected with life-limiting/life-threatening illnesses and their families. It focuses on the physical, psychosocial, and spiritual needs of the child and the family. It is initiated at diagnosis of a life-limiting illness and must continue all through the illness. Bereaved family is supported after child's death.⁹

Provision of Palliative Care Services for Children

Palliative care services for children can be provided in any setting such as a hospital, daycare center, community, and home. Palliative care for the majority of children suffering from life-threatening illnesses can be provided by a health-care provider with a basic or intermediate level of training. Specialists in other fields, such as pediatrics, oncology, and intensive care, can provide palliative care with an intermediate level of training in palliative care and can integrate it with their usual practice. Children with complex symptoms and problems may require the intervention of a specialist in palliative care who leads the palliative care interdisciplinary team.⁹

Difference between Palliative Care of Adults and Children

The aim of palliative care for both adults and children is to improve the quality of life of patients/family members and relieve the suffering of patients. Both follow same bioethical principles, but we should remember that children are not little adults. Involvement of palliative care services for children should be relatively earlier compared to adult patients. Children require developmentally appropriate care as per their physiological and psychological maturity. They have special needs and respond differently to the disease and its treatment. Children are generally dependent on their parents or caregivers. Communicating with children also requires a unique set of skills as per their level of understanding. The role of family is much more while caring for the children. It is essential to proactively engage the family members in the care of child and provide respite care to parents/family members as required. Therefore, it is crucial to recognize the difference between adult and children's palliative care and provide the care accordingly.¹⁰

Role of Nurses in Palliative Care of Children

The role of nurses in the PCC is multifaceted. They play variety of roles, such as direct care provider, communicator, patient advocate, respite nurse, and counsellor (► Fig. 2).

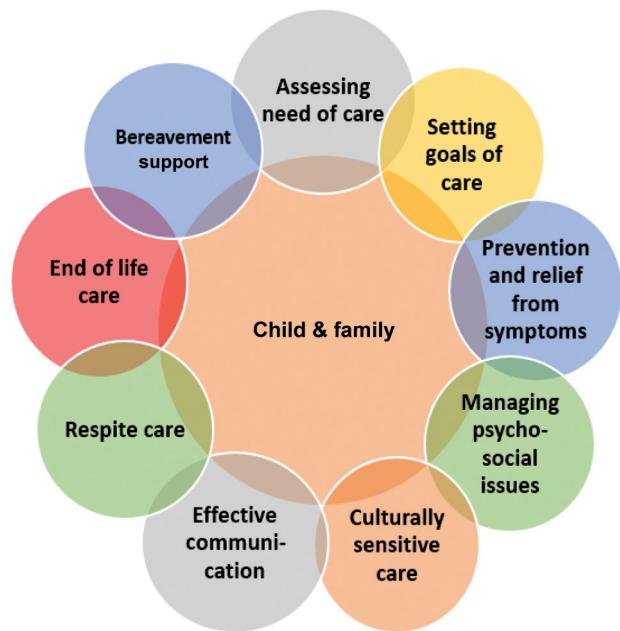


Fig. 2 Role of nurses in palliative care of children.

Assessing the need of care: Nurses spend maximum time with the patient and are in a vital position to determine the care requirements of the patient and family. Head-to-toe physical examination and psychosocial evaluation are required to establish the need of care.

Setting goals of care: Nurses should set realistic goals of care as per the patient's prognosis and have discussions with parents and family members. Nurses should guide the patient and family in setting the goals of care. Physical, psychosocial, and spiritual domain of care should be considered for setting up the goals.^{11–13}

Prevention and relief from physical symptoms: Pain and other symptoms should be assessed and managed promptly. Unrelieved pain and other symptoms may deter the quality of life of the patient. Pain should be assessed and reassessed using age-appropriate tools (e.g., faces pain scale, numeric rating scale). Pain management should be based on the World Health Organization (WHO) ladder. Nonpharmacological interventions such as massage, distraction, and guided imagery, may also be helpful. Other symptoms, such as fatigue, nausea, vomiting, loose stools, constipation, should be appropriately managed to reduce the physical distress of the child. It will help to improve the quality of life of the child and family. Parents and family members should also be empowered to self-manage the symptoms.^{3,4}

Managing psychosocial issue: Nurses should honestly address the fears and concerns of the child and family. Their care preferences should be respected. Parents should be empowered to care for their children through the health education and information. They can be introduced to self-help groups to get social support. Nurses can guide them to contact medial social welfare officers to get the financial assistance from the government agencies and nongovernment organizations (NGOs).^{4,14}

Respecting cultural and religious belief: It is important to consider assessing religious beliefs, customs, or food habits to prevent conflict. Sometimes healthcare providers cannot understand the parent's perspective due to language barriers and cultural differences. Nurses should get an insight into the culture of parents and family and undergo training to understand the cultural perspective of the community they are serving. Parents and family should be involved in decision-making and culturally sensitive care should be provided. Nurses should provide psychological and spiritual support to the patient and the family members.^{15,16}

Effective communication: Good communication is a therapeutic instrument that is required to demonstrate affection, attention, and sensitivity toward children affected by life-threatening illness and their family members. The nurses should adopt developmentally appropriate strategies while communicating with the children. The nurses should establish an agreement about the time. The play way method can be used to engage the child and explore the need. Medical information can be communicated as per the level of development of the child. We should be empathetic and should encourage the child to express his/her feelings.^{17,18}

Respite care: Respite care is giving a break to the caregivers (parents or family members) from the care responsibilities of their sick child. Respite care allows family members to enjoy some simple pleasures and perform other important family tasks. It can be provided in daycare centers or hospitals or at home where a specially trained healthcare professional takes care of the child. Nurses can assume the role of respite nurse to help family members to provide some relief to the family.^{19,20}

End of life care: When nurses are informed about a child's imminent death, they should keep the child separate from other children. Parents should be informed in a very empathetic way. Maximize the comfort of the child by managing pain or other symptoms promptly. Parents should be allowed to stay with the child and interact more. Nurses should educate and counsel the parents and family members to be emotionally prepared for the expected condition. News of death to the parents/ family should be given in a calm and quite manner, assuring the parents that the health team provided the child with the best possible treatment and care. Religious and cultural belief of the parents and family should be respected while caring for the child after death.²¹

Bereavement support: The death of a child is one of the most traumatic experience, and bereavement continues for a lifetime. Healthcare professionals, particularly nurses, may help to parents/family and siblings by providing them with robust and tailored bereavement support. Several strategies are used to provide bereavement support, including follow-up over telephone, house visits, personal visits, cards, legacy creation, self-help initiatives, and family counselling.^{4,22}

Implications for Nursing Science

PCC has numerous implications for nursing practice, nursing education, and nursing research (► Fig. 3).

Nursing Practice

The nurses are in an ideal position to help the patient and caregivers in setting care goals for the child and advocate with the medical team to ensure that these goals are consistently followed across all healthcare services. This may be a new role for advanced practice registered nurses. Efficient palliative care strives to minimize the physical, psychosocial, and spiritual distress inflicted by life-limiting conditions. Nursing care for children requiring palliative care should be focused on the principles of humanization. There should be connect between care and emotions of patients. Nurses should try to form a nurse-child-family bond. The nurses are having pivotal role in recognizing different types of suffering, advocating for providing appropriate treatment, and evaluating the effectiveness of such treatments. Nurses should bust the myth and misconception of family members regarding palliative care. Support from NGOs and other community organization may help bridge the care gap between hospitals and homes. Nurses can be instrumental in educating the family members about available community resources.^{23–25}

Nursing Education

Palliative care nursing holds a specific role in the pediatric patients with life-limiting illness but it is not adequately covered in the nursing curriculum. Standardized education and in-service training should be provided to serving nurses to equip them with required knowledge and competencies.²⁶ In addition, professional schools must commit to the

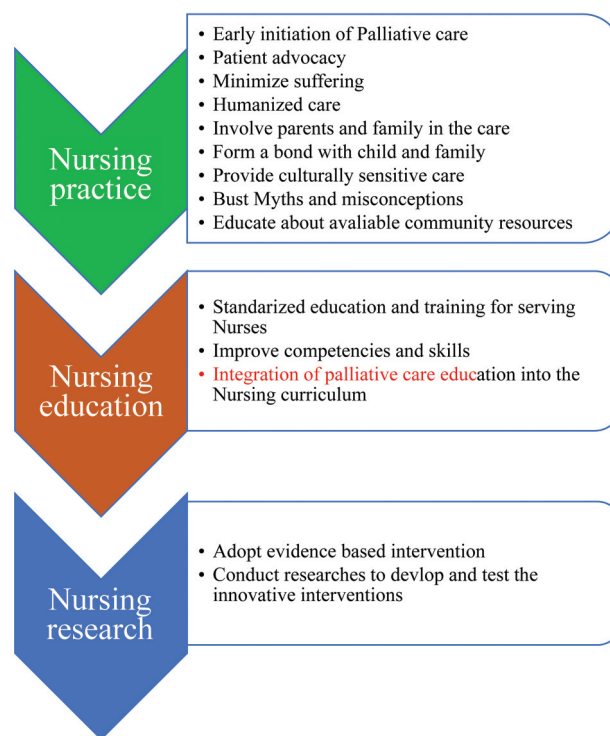


Fig. 3 Implication for nursing sciences.

integration of palliative and end-of-life education into the curriculum.^{27,28}

Nursing Research

The dearth of research in this field is a result of an absence of attention to the needs of children with life-limiting illnesses and their caregivers. This lack of research is surprising, given the global impact of life limiting diseases. The evolution of PCC must take into account medical, psychosocial, and spiritual requirements of child and family; hence, new research is required to establish the best evidence to cater for this population. This highlights a need for further research on this important area. Nurse researchers should conduct more studies to better understand how to improve the quality of life and lessen discomfort for these susceptible kids and their family members who are at a significant risk of unfavorable outcomes.^{23–25}

Conclusion

PCC is a broad multidisciplinary approach that starts with the diagnosis of illness and continues throughout the illness, irrespective of the prognosis. Its objective is to enhance the child's and family's quality of life. Nurses must understand their role in the PCC and distinguish it from hospice and end-of-life care. A nurse's perspective as a part of a multidisciplinary treatment team is distinct, because of their training in holistic patient care. They act as direct care provider, communicator, patient advocate, respite nurse, counselor etc. PCC should be adequately incorporated into the nursing curriculum, and standardized education and in-service training should be provided to serving nurses to equip them with required knowledge and competencies. Nurse researchers should be encouraged to conduct studies to generate evidence-based nursing interventions to help the children requiring palliative care and their family members.

Conflict of Interest

None declared.

References

- Standards of Practice for Pediatric Palliative Care and Hospice Published online 2022. Accessed April 21, 2023 at: <https://www.nhpco.org/pediatrics/>
- Connor SR, Bermedo MCS. Worldwide Hospice Palliative Care Alliance, World Health Organization. Global Atlas of Palliative Care; 2020
- Muckaden M, Dighe M, Balaji P, et al. Paediatric palliative care: theory to practice. *Indian J Palliat Care* 2011;17(Suppl): S52–S60
- Docherty SL, Thaxton C, Allison C, Barfield RC, Tamburro RF. The nursing dimension of providing palliative care to children and adolescents with cancer. *Clin Med Insights Pediatr* 2012;6:75–88. Doi: 10.4137/CMPed.S8208
- De Clercq E, Rost M, Rakic M, et al. The conceptual understanding of pediatric palliative care: a Swiss healthcare perspective. *BMC Palliat Care* 2019;18(01):55. Doi: 10.1186/s12904-019-0438-1
- Johnston DL, Vadeboncoeur C. Palliative care consultation in pediatric oncology. *Support Care Cancer* 2012;20(04):799–803
- Ranallo L. Improving the quality of end-of-life care in pediatric oncology patients through the early implementation of palliative care. *J Pediatr Oncol Nurs* 2017;34(06):374–380
- National Quality Forum A National Framework and Preferred Practices for Palliative and Hospice Care Quality: A Consensus Report. National Quality Forum; 2006
- World Health Organization Integrating Palliative Care and Symptom Relief into Paediatrics: A WHO Guide for Health-Care Planners, Implementers and Managers. World Health Organization; 2018. Accessed April 21, 2023 at: <https://apps.who.int/iris/handle/10665/274561>
- Chelazzi C, Villa G, Lanini I, Romagnoli S, Latronico N. The adult and pediatric palliative care: differences and shared issues. *J Anesthesia Analgesia Crit Care* 2023;3(01):1. Doi: 10.1186/s44158-023-00085-8
- Kochen EM, Boelen PA, Teunissen SCCM, et al; emBRACE Working Group. Health care professionals' experiences with Preloss care in pediatrics: goals, strategies, obstacles, and facilitators. *J Pain Symptom Manage* 2021;62(01):107–116
- Tamburro RF, Shaffer ML, Hahnen NC, Felker P, Ceneviva GD. Care goals and decisions for children referred to a pediatric palliative care program. *J Palliat Med* 2011;14(05):607–613
- Williams LJ. Palliative care and population management: utilization of palliative care in pediatric critical care nursing. *Crit Care Nurs Clin North Am* 2022;34(01):13–18
- Weaver MS, Heinze KE, Bell CJ, et al; Pediatric Palliative Care Special Interest Group at Children's National Health System. Establishing psychosocial palliative care standards for children and adolescents with cancer and their families: an integrative review. *Palliat Med* 2016;30(03):212–223
- Wiener L, McConnell DG, Latella L, Ludi E. Cultural and religious considerations in pediatric palliative care. *Palliat Support Care* 2013;11(01):47–67
- Suurmond J, Lieveld A, van de Wetering M, Schouten-van Meeteren AYN. Towards culturally competent paediatric oncology care. A qualitative study from the perspective of care providers. *Eur J Cancer Care (Engl)* 2017;26(06):. Doi: 10.1111/ecc.12680
- Hendricks-Ferguson VL, Sawin KJ, Montgomery K, et al. Novice nurses' experiences with palliative and end-of-life communication. *J Pediatr Oncol Nurs* 2015;32(04):240–252
- França JR, da Costa SF, Lopes MEL, da Nóbrega MM, de França IS. The importance of communication in pediatric oncology palliative care: focus on Humanistic Nursing Theory. *Rev Lat Am Enfermagem* 2013;21(03):780–786
- Ling J. Respite support for children with a life-limiting condition and their parents: a literature review. *Int J Palliat Nurs* 2012;18(03):129–134
- Smith CH, Graham CA, Herbert AR. Respite needs of families receiving palliative care. *J Paediatr Child Health* 2017;53(02): 173–179
- Ebadinejad Z, Fakhri-Movahedi A. Palliative care strategies of Iranian nurses for children dying from cancer: a qualitative study. *East Mediterr Health J* 2022;27(08):577–583
- Schuelke T, Crawford C, Kentor R, et al. Current grief support in pediatric palliative care. *Children (Basel)* 2021;8(04):278. Doi: 10.3390/children8040278
- Akard TF, Hendricks-Ferguson VL, Gilmer MJ. Pediatric palliative care nursing. *Ann Palliat Med* 2019;8(1, Suppl 1):S39–S48
- Sousa ADRSE, Silva LFD, Paiva ED. Nursing interventions in palliative care in pediatric oncology: an integrative review. *Rev Bras Enferm* 2019;72(02):531–540
- Pyke-Grimm KA, Fisher B, Haskamp A, Bell CJ, Newman AR. Providing palliative and hospice care to children, adolescents and young adults with cancer. *Semin Oncol Nurs* 2021;37(03): 151166. Doi: 10.1016/j.soncn.2021.151166
- Abuhammad S, Almasri R. Impact of educational programs on nurses' knowledge and attitude toward pediatric palliative care. *Palliat Support Care* 2022;20(03):397–406

- 27 O'Shea ER, Campbell SH, Engler AJ, Beauregard R, Chamberlin EC, Currie LM. Effectiveness of a perinatal and pediatric End-of-Life Nursing Education Consortium (ELNEC) curricula integration. *Nurse Educ Today* 2015;35(06):765–770
- 28 Chong L, Abdullah A. Community palliative care nurses' challenges and coping strategies on delivering home-based pediatric palliative care. *Am J Hosp Palliat Care* 2017;34(02):125–131