

Issues, Challenges, and Potential of Palliative Care in Pediatric Nursing: A Systematic Review

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ABSTRACT

Background: Palliative care is an essential right for infants and children with a life-threatening illness. However, palliative care is still unavailable in some developing countries. This study aimed to explore the issues, challenges, and potential of palliative care in pediatric nursing care.

Subjects and Method: A systematic review was conducted by searching published articles in PubMed, CINAHL, and EMBASE databases, from year 2000 to 2018. The keywords used for this study included “palliative” AND “children”, “palliative” AND “nursing” AND “care”, “palliative care” AND “pediatric care”. The data were analyzed by PRISMA flow diagram.

Results: Palliative care is evolving continuously, meeting new challenges, and expanding beyond the care of terminally ill pediatric patients. A major challenge in palliative care is effective communication. However, only a few communication trainings exist for nurses. Obstacles of palliative care in pediatrics nursing included clinical, ope-

ration, and financial factors. However, palliative care has a substantial potential to reduce morbidity in infants and children. In addition, a cohort study conducted in 265 pediatric cancer patients reported that palliative care reduced pain and improved their life expectancy.

Conclusion: Palliative care is a comprehensive approach of care and its delivery to pediatric patients is challenging. It has a substantial potential in reducing infant and child morbidity.

Keywords: palliative care, pediatric nursing, palliative nursing

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BACKGROUND

Every year, more than 500,000 babies and children struggle against life-threatening diseases and limit lives with uncertain trajectories. They suffer from advanced disease and do not know access to health services that can help relieve pain, reduce symptoms and overcome psychosocial problems that even occur in their families (Williams-Reade et al., 2015).

Overcoming this, developed countries have optimized palliative care and it is estimated that every year, 7 million families

benefit. Palliative care for children and young adults is defined as active and total care for the body, mind, spirit, and family, from a diagnosis that limits life to death (Amery, 2012).

The International Children's Palliative Care Network (ICPCN) 's has defined conditions that limit life as conditions for which there is no reasonable hope to cure patients either children or adults from the condition of their illness and they only carry out curative steps that are very likely to fail (Marston et al., 2018).

Palliative care is also defined as patient-centered care to improve the quality of life along the trajectory of the disease, relieve symptoms, discomfort, and stress for children living with life-threatening conditions and their families (Akard et al., 2019).

Furthermore, palliative care is a comprehensive approach that addresses physical, emotional, social and spiritual elements, focusing on care coordination, quality of life for children and support for families starting at diagnosis and continuing throughout care, death and during mourning (Chambers, 2003; Amery, 2012).

Previous studies have reported that in Indonesia there is still a serious lack of care and improvement in the quality of hospital care for infants and children, with qualitative data showing major problems including: the use of inadequate standard treatment guidelines, irrational prescription of antibiotics, monitoring poor progress and poor supportive care (Sidik et al., 2013). So that palliative care is very likely to be applied and also developed in Indonesia.

However, palliative care also still has some obstacles and challenges to apply. Based on the problem above, the purpose of this review is to discuss the obstacles, challenges and potential of palliative care in pediatric services.

SUBJECTS AND METHOD

1. Study Design

A systematic review was carried out by searching for articles published in the PubMed, CINAHL, and EMBASE databases, from 2000 to 2018. Keywords used for this study included "palliative" AND "children", "palliative" AND "nursing" AND "care", "Palliative care" AND "pediatric care". The data were analyzed with a PRISMA flowchart.

2. Inclusion and Exclusion Criteria

Criteria for articles included in this review were randomized controlled trials, retrospective, observational studies, case studies, reviews, systemic reviews, and meta-analysis. The articles excluded in this study were non-full text article.

3. Data extraction

The searchers on electronic databases were filtered to identify studies that include relevance for reference. Then the data was made into a structured table i.e. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA).

RESULTS

Based on PRISMA, a total of 275 articles were identified during the initial search of the entire database. After eliminating duplication and applying selection, 10 articles will be analyzed for further qualitative discussion.

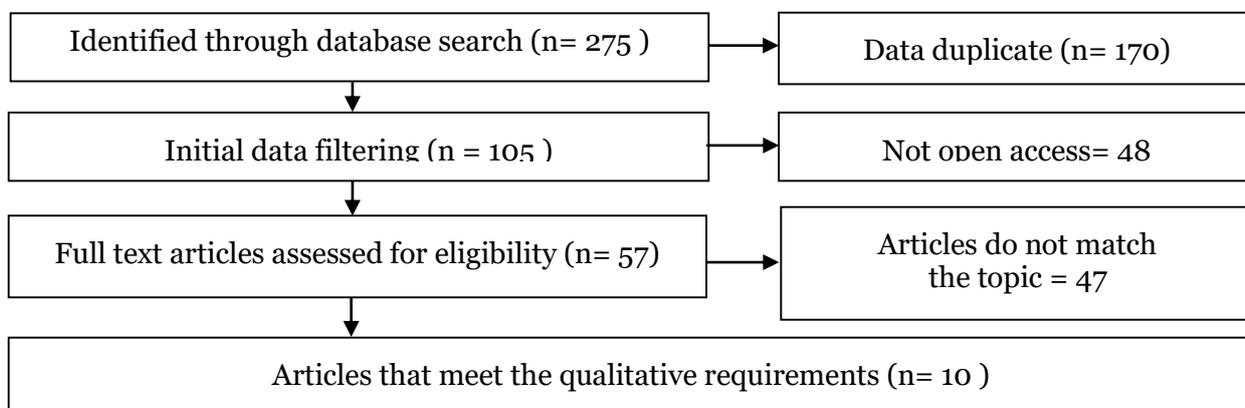


Figure 1. PRISMA of Systematic Review

1. Obstacles

Previous research has reported several challenges and obstacles in the implementation and development of palliative care in children including:

a. Clinical factors

A common challenge for doctors, patients and family members in understanding the clinical goals of palliative care, when treatment is started, and the selection of appropriate care (Williams-Reade et al., 2015).

Palliative care focuses on comfort care while simultaneously providing curative care. Patients who receive palliative care do not need to be seriously ill. Palliative care can be given at any time during the patient's illness. It can begin at the time of diagnosis, undergoing treatment, or during lifelong care (Kirk and Mahon, 2010).

Determination of palliative care needs is also different for children and adults. Caring for children requires physical, emotional, social, cognitive and spiritual development, which means that they receive more aggressive and complicated care compared to adults. However, not many experienced professionals have the ability and qualifications to carry out this treatment (Meier and Beresford, 2007; Williams-Reade et al., 2015).

b. Lack of resources

In addition, the lack of local resources often results in children and their families traveling long distances to health care facilities, so that children are separated from their social environment that actually supports healing, so that it can threaten to disturb the child's condition (Williams-Reade et al., 2015).

c. Operational factors

Inadequate preparation and guidance for health workers makes doctors and nurses rarely receive training and opportunities to practice the skills needed to communicate effectively with dying children and their families (Kersun et al. 2009, Sheetz and Bowman

2008, Yang et al. 2011).

Training and materials related to palliative care were not provided adequately to doctors, due to lack of time and educational facilities and mentors or teaching staff (Michelson et al., 2009; Williams-Reade et al., 2015).

Previous studies have reported that when pediatric patients and their families go home, they may have to rely on health workers with limited experience in treating children with advanced disease or unable to provide palliative care (Williams-Reade et al., 2015).

d. Financial factors

Financial barriers related to payment and reimbursement. Research reports the majority of children who die have never benefited from receiving palliative care services due to financial problems (Lindley et al. 2009).

The payment and reimbursement model for palliative care in children is also quite complex and often inadequate. Children insured with a variety of private or state insurance have significant variation in coverage and do not have the same consistency in the replacement of palliative care (Friebert, 2009; Williams-Reade et al., 2015).

In addition, children who receive palliative care often live longer than adults so the financial burden of care on their families is higher (Friebert, 2009).

2. Challenges

Children with life-limiting diseases need complex care. However, lack of communication and coordination between health services and the social environment often occurs in the current health care system (Browning and Solomon 2005; Williams-Reade et al., 2015).

Care coordination and collaboration between disciplines during care is very important to optimize palliative services, however, more important coordination is between patient and family and good commu-

nication between family members and medical staff, because palliative care of a patient's child usually requires community-based care (Hinds et al., 2005; Hays et al., 2006; Williams-Reade et al., 2015).

In addition, health professionals, government agencies and other relevant parties must work together to develop and implement further guidelines and procedures for palliative care (Williams-Reade et al., 2015).

3. Effectiveness of palliative care

A 5-year retrospective cohort study conducted by Thrane et al. (2017) reported that of 256 children. Forty-eight children, especially cancer sufferers, experienced a decrease in post referral pain, three days before and after the administration of palliative care ($p < 0.05$).

DISCUSSION

Palliative care is a complex program and requires collaboration between patients, families, and the community and health care providers. The success of the treatment depends on the operational, financial and clinical aspects that are well managed.

Palliative care refers to patient- and family centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and facilitating patient autonomy, access to information, and choice.

The purpose of palliative care is to provide aggressive symptom management, supported decision making, and, when appropriate, optimal end-of-life care. Palliative care is family-centered although in those cases in which the needs and preferences of the family counter the best interests of the patient, the needs of the patient are primary. In rare cases where patient suffering is especially resistant to other forms of treatment, one of the therapies available to palliative care teams is

palliative sedation. Palliative sedation is the lowering of patient consciousness using medications for the express purpose of limiting patient awareness of suffering that is intractable and intolerable. For the limited number of imminently dying patients who have pain and suffering that is (a) unresponsive to other palliative interventions less suppressive of consciousness and (b) intolerable to the patient, NHPCO believes that palliative sedation is an important option to be considered by health care providers, patients, and families. As this practice continues to be addressed in the professional and lay literatures, discussion of palliative sedation is often framed in ethical terms.

The following statement and commentary seek to clarify the position of NHPCO on the use of palliative sedation for patients at the end of life, recommend questions and issues to be addressed in each case for which palliative sedation is being considered, and assist health care organizations in the development of policies for the use of palliative sedation. This statement addresses the use of palliative sedation only for patients who are terminally ill and whose death is imminent (Kirk et al., 2010).

Hospital staff, policy makers, health service providers and researchers must be aware of the various aspects that will improve the provision of palliative care for children and work to fulfill these aspects (Williams-Reade et al., 2015).

Palliative care is care with a comprehensive approach and service delivery for pediatric patients that is still very difficult, but this treatment has great potential in reducing infant and child morbidity by focusing on what resources are needed in each aspect (Williams-Reade et al., 2015).

AUTHORS CONTRIBUTION

Aris Widiyanto, Rina Tri Handayani, and Joko Tri Atmojo, collected and examined the

articles, and wrote the systematic review, with about equal contribution.

CONFLICT OF INTEREST

There is no conflict of interest in this study.

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