

Conference Paper

A Systematic Review: What Are the Barriers for Nurses in Providing End of Life Care for Pediatric Patients?

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Abstract

Background: Providing care for children at the end-of-life is challenging and distressing for nurses and healthcare professionals. It is important to identify matters that might be a barrier in providing end-of-life care (EOLC). **Objectives:** A review of the literature focusing on the barriers in providing EOLC for pediatric patients. **Methods:** Literature published from 2009 to 2019 was obtained from four databases (Academic Search Complete, CINAHL, MEDLINE, and Science Direct) and critically reviewed using Joanna Briggs Institute (JBI) critical appraisal tools. Primary research studies written in English describing barriers experienced by nurses on EOLC provision which published between 2009-2019 were included. **Results:** Ten studies met the inclusion criteria. The barriers perceived by nurses in these studies are communication and language barriers; barriers in interdisciplinary team; lack of knowledge; families who cannot accept the child's poor prognosis; financial needs; nurses' feeling; aggressive intervention received by the patient; and inadequate hospital facilities. **Conclusions:** Nurses enact a crucial role in caring for dying children and the children's families. Overcoming barriers in EOLC provision could greatly improve the quality of end-of-life care for dying children. Therefore, it is necessary to develop a conceptual model to support nurses and health care professionals in providing EOLC for pediatric patients.

Keywords: Barriers, end-of-life care, nurses, pediatric

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1. Introduction

End-of-life care (EOLC) is an important method of care for infants and children with terminal illness through the prevention or alleviation of physical, emotional, social, and spiritual suffering [1]. Providing care for children at the end-of-life is challenging and distressing for nurses and healthcare professionals [2]. Since the death of a child is devastating event for a family and especially for the child's parents [3]. Pediatric nurses spend the most time with the patient and his or her family and this intensity of time and patient care leads to a very close relationship between the nurse and the family and they have to deal more directly with the dying process [4]. Therefore, nurses have a prominent role throughout the family's journey from diagnosis to post-bereavement

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and this role might be one of the most difficult that nurses have to encounter in their career [5].

There are numerous obstacles and challenges which nurses have to face while providing EOLC to pediatric patients and their families [6]. Barriers that might have to be faced by nurses can be from various aspects. The palliative care team for pediatric patients includes people from many disciplines based in both inpatient and/or outpatient settings [7]. From the beginning of their training and education, nurses and physicians have a different focus, nurses are taught to provide holistic care to the patient, whereas physicians' training is focused on diagnostic skills that may enable a patient to be cured [8]. Therefore, this situation might induce a barrier in interdisciplinary regarding the provision of care for the patient due to the difference of perspectives. When conflict and moral distress are noticed as barriers to effective palliative care in the literature, improved communication between members of the health care team is a recommended solution and this in turn might help nurses and physicians to comprehend each other's differing perspectives [9,8,10], stated that good quality of communication at the end of a child's life fosters trust between families and staff and helps to ascertain that the dying child receives the best possible care.

Barriers continue to exist in providing quality end-of-life care, and some clinicians seem impervious to change despite the evidence that exists about the provision of a good death [1]. From the metaphysical to the practical, health care professionals are confronted with barriers that hinder optimal end-of-life care in pediatric [11]. Hence, it is important to identify matters that might be a barrier in providing EOLC. An appropriate understanding of these barriers is required to formulate a new working guide to EOL care delivery [11]. A multidisciplinary team of clinicians and researchers should investigate ways of integrating these results into interventions that might decrease or eliminate barriers to providing end-of-life care and enhance or support helpful care practices at the end of life [1]. Consequently, barriers are crucial to be identified so that it can be overcome and the quality of EOLC provided can be optimal.

2. Methods

2.1. Study design

A review using systematic methods of literature pertaining to barriers in providing EOLC for pediatric patients.

2.2. Search strategy

A variety of electronic databases were searched including MEDLINE, CINAHL, Academic Search Complete, and Science Direct. The PICO framework was used to identify the keywords in the review question [12]. Initial keywords was utilize the MeSH term that commonly used. Article searching was used with keywords 'pediatric', 'end-of-life care', 'barriers', 'obstacles', 'challenges', 'difficulties', 'issues', and 'nursing'. These were then incorporated alongside Boolean operators and truncation marks in order to gain all the articles related to the topic.

2.3. Inclusion/exclusion criteria

In order to obtain the most relevant articles the following criteria were utilized (1) articles published between 2009-2019 in order to maintain modernity, (2) articles reviewed were published in English language, (3) Articles focussed on the barriers in providing EOLC for pediatric patients, (4) All research methodologies were included in the review to obtain as much as existing research-based literature, (5) reviews were excluded.

2.4. Data extraction

These articles varied in study design from quantitative, qualitative, mixed quantitative and qualitative analysis to case study. Data were entered into common tables to be presented and potentially compared and make recommendations for consistency in future data collection. The common data extraction headings were authors, aims, methods, participants, and findings. A review of the articles was undertaken by using the Critical Appraisal Tools from The Joanna Briggs Institute (JBI)

3. Results

A total of 10 articles that met the search strategy and inclusion criteria were retrieved and analyzed. The PRISMA flow chart is reported in Fig.1.

The literature searches generated 2106 records through searches of electronic databases, excluding duplicates (1173). From above number, we exclude the studies that were not pediatric patients, not end-of-life care, not focussed on barriers and not meet study design (34). For total reviewed the full text of the remaining 10 records was eligible. Finally, author only included 10 studies to be reviewed.

The review regarding to barriers in providing EOLC for pediatric patient comprises one case study, five descriptive quantitative studies, three qualitative studies, and one mixed-methods study. The result of analysis of the study in this review is reported in Table 1.

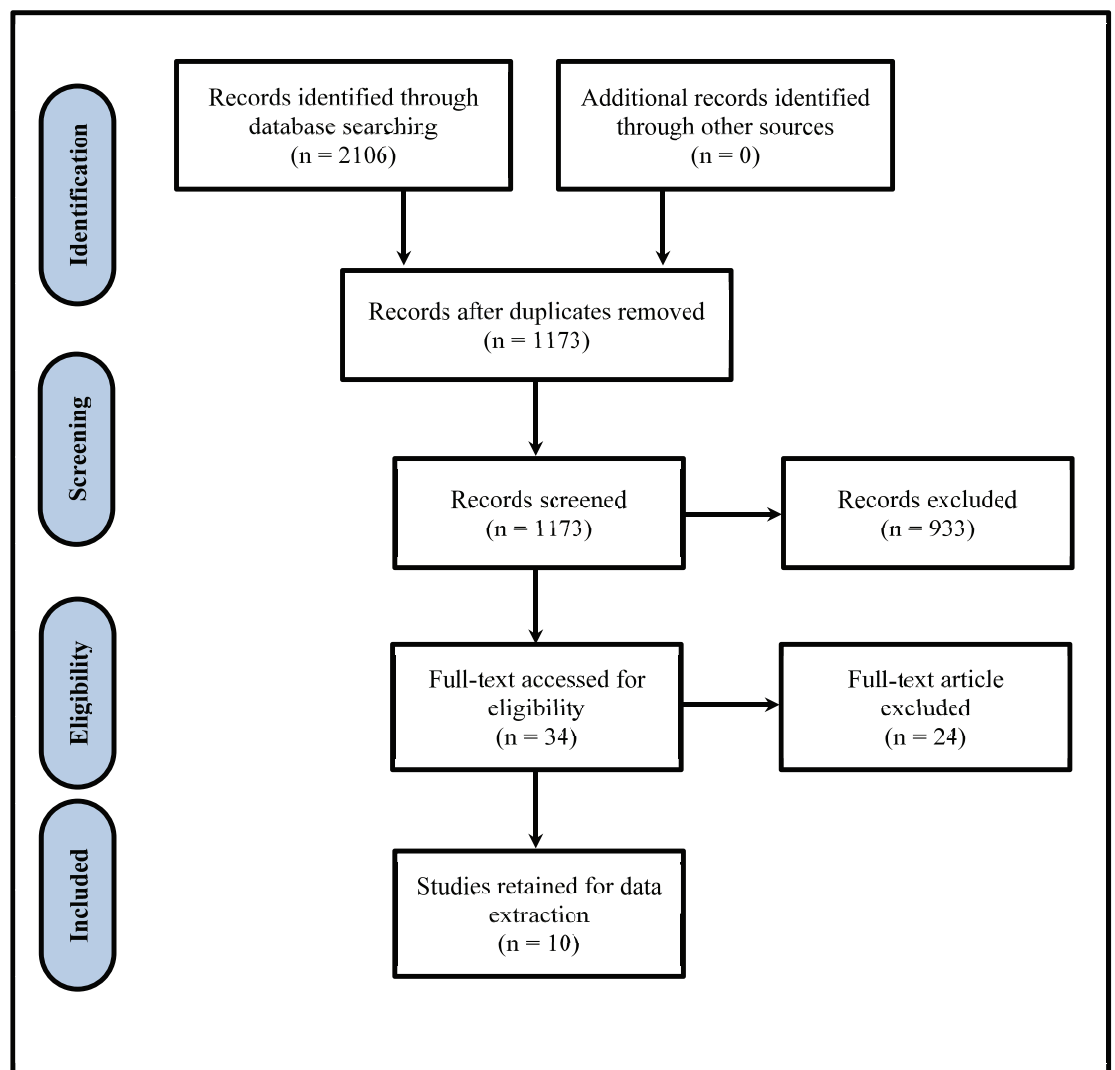


Figure 1: PRISMA flow diagram describing process of articles being reviewed and selected.

TABLE 1: Analysis of the study.

Author	Aims of Study	Partisipant	Method	Results
Martin (2013)	To identify barriers faced by members of the neonatal team	Patient named Seth (anonymity)	Case study	Barriers faced by members of neonatal team are: Fear of respiratory depression surrounding opiate use at the end of life, conflict among members of the care team leading to moral distress, and inadequate training and support for staff.
Iglesias, Pascual, and Vallejo (2013)	To identify aspects of care that health professionals consider to be either facilitators or barriers to providing good care to patients and their families in end-of-life situations.	staff nurses with at least 3 months of experience working in adult or pediatric intensive care units in 2 high-complexity hospitals of the Sanitary Public of Madrid, Spain.	Descriptive study	The largest obstacles to be: (1) when physicians are evasive and avoid the family (2) when the terminally ill patient experiences a painful intervention (3) when the family is not accepting of a poor prognosis.
Esmaili, Stewart, Masalu, and Schroeder, (2018)	To identify strengths that could help overcome these complex barriers, to inform the development of culturally appropriate palliative care policies for children in Tanzania and in similar settings globally	Twenty caregiver and fourteen staff.	Qualitative study	Barriers to palliative care for pediatric are: Financial barriers, infrastructure, barriers, knowledge and Culture Barriers

Author	Aims of Study	Partisipant	Method	Results
Curcio (2017)	To explores the lived experiences of nurses caring for dying pediatric patients.	9 pediatric nurses	Qualitative phenomenological study	Seven themes emerged to describe the phenomenon of nurses caring for dying pediatric patients: a) empathy, b) feelings of ambivalence c) inevitability d) inspiration e) relationship f) self-preservation g) sorrow.
Mesukko (2010)	To explore nurses' perceptions of the quality of dying and death, barriers and facilitators to providing pediatric end-of-life care in Thai Intensive care Units.	129 neonatal and pediatric ICU nurses from two university hospitals in Thailand	Descriptive correlational design	Barriers were grouped into three main categories: patient-family-related barriers, healthcare-professional-related barriers and organizational-related barriers.
Iranmanesh, Banazadeh, and Forozy (2014)	To determine pediatric nurses' perceptions of intensity, frequency occurrence, and magnitude score of selected barriers in providing pediatric end-of-life care	151 Staff nurses working in pediatric units including pediatric general units, pediatric oncology units, pediatric intensive care unit, and pediatric emergency units in 2 hospitals	Cross-sectional descriptive study	The highest/lowest perceived barriers magnitude scores were families not accepting poor child prognosis and continuing to provide advanced treatment to dying child because of financial benefits to the hospital.
Khraisat, Alakour, and O'Neill (2017)	To identify the barriers and facilitators to provide pediatric end-of-life care	Two hundred critical care nurses	Descriptive cross-sectional study	The highest scoring of barriers respectively were having deal with angry family member; multiple physicians, involved with one patient; and not available support person for the family.

Author	Aims of Study	Partisipant	Method	Results
Beckstrand, Rawle, Callister, and Mandleco, (2010)	To determine pediatric intensive care unit nurses' perceptions of sizes, frequencies, and magnitudes of selected obstacles and helpful behaviors in providing end-of-life care to children.	A national sample of 1047 pediatric intensive care unit nurses who were members of the American Association of Critical-Care Nurses.	Descriptive quantitative study	The two items with the highest perceived obstacle magnitude scores were language barriers and parental discomfort in withholding and/or withdrawing mechanical ventilation.
Bergsträsser, Cignacco, and Luck, (2017)	To describe the experiences and needs of health care professionals in pediatric end-of-life care in Switzerland and to develop recommendations for the health ministry	48 participants were conducted, comprising 17 physicians, 18 nurses, 6 community nurses, 4 social workers, a psychologist, a music therapist, and a chaplain.	A qualitative interpretative approach	Barriers to this interaction were ethical dilemmas, problems in collaboration with the interprofessional team, and structural problems on the level of organizations.
Bloomer, O'Connor, Copnell, and Endacott, (2015)	To explore how neonatal and pediatric intensive care unit nurses care for families before and after death; to explore the nurses' perspectives on their preparedness to provide family care; and to determine the emotional content of language used by nurse participants	22 registered nurses from neonatal and paediatric intensive care units of two major metropolitan hospitals in Australia	Mixed methods study	Four core themes were identified: preparing for death; communication challenges; the nurse-family relationship and resilience of nurses. Findings suggested that continuing to provide aggressive treatment to a dying child/infant whilst simultaneously caring for the family caused discomfort and frustration for nurses.

4. Discussion

Based on the review of the studies, the barriers perceived by nurses in providing EOLC for pediatric patient fell into several themes.

4.1. Communication and language barriers

Communication and language was perceived as barriers by nurses in eight out of ten studies reviewed. Difficulty with communication between health care professionals and patient is difficult when caring for children, and it already began when a serious diagnosis need to be discussed and bad news delivered to a child and his or her parents [13,4]. In study conducted by Esmaili et al. (2018), a lack of communication between staff and terminally ill patients can be caused by the cultural norms that dictated these communication patterns which does not allow staff to mention dying, even when that is the case [14], Moreover, deal with angry family member situation might also be a barrier for nurses to provide pediatric EOLC since nurses must have time to listen when family need to express their feelings, to provide comfort and talk openly and honestly about grief [15]. Barriers in this communication may occur when physicians are evasive and avoid the family [16].

Nurses are an important part of the health care team and play an essential role in clinician-family communication to overcome language and communication barriers with children's families and between interdisciplinary team members so that it could greatly improve the end-of-life experience for dying children [13]. To overcome the communication barriers with the family and within the interdisciplinary team, required interprofessional collaboration, with physicians leading end of life discussions. Irrespective of who was communicating with the family, the important thing was keeping child at the centre of all communication in a way that acknowledged their life, and the child should be involved in this process as much as its developmental stage and health condition allowed, so that it can positively affect end-of-life care [13,14,17]. Therefore, nurses need to develop specific communication skills, which comprises effective and open communication to identify infants and families with a palliative care need and focus on preparing families for the death of their child and also improve communication among the health care team, thereby reducing the occurrence of conflict and moral distress [17,18].

4.2. Barriers in interdisciplinary team

In several studies, nurses reported that the health care professional related barrier to provide pediatric end-of-life care was multiple physicians or health care professionals do not have the same perspectives about the direction care or treatment plans [15,18,19]. Conflict between health care team, ethical dilemmas in collaboration, and being ignored

by other members may lead to considerable stress among team members, such as sense of powerlessness and frustration that might occur when health care professionals do not share the same perspectives and goals for a patient [13,17,18].

Another barrier related to interdisciplinary team was no available support person for the family such as a social worker or religious leader [20,15,19]. Nurses have to concurrently deal with patients whose lives are being maintained and those whose lives are ending, they might feel it is excessively to tolerate these situations alone. Thus, they need support and assistance from other discipline such as social workers or religious leaders in moving through the pediatric EOLC process with their patients [15]. A well established interdisciplinary team may find a mutual understanding of what ultimately is best for a child [13].

4.3. Lack of knowledge

Lack of knowledge, inadequate training, lack of skill to approach dying patient and family and guidelines in EOLC were also described as barriers to providing pediatric end-of-life care [4,18,19]. End-of-life care without knowledgeable and skilled physicians and nurses is unable to guarantee the best quality of care for a dying child [19]. Therefore, nurses need to be well prepared and trained to overcome such challenging and emotionally draining responsibilities as those encountered in pediatric EOL care [4].

4.4. Families who cannot accept the child's poor prognosis

Pediatric nurses also perceived the barrier when the family is not accepting of a poor prognosis [16,20,19]. Denying the fact that the child had a poor prognosis is a coping strategy for family to tolerate this great grief [20]. Nurses believe that it is difficult when families do not accept the prognosis, hence it is important to help families comprehend the need to respect the wishes of the patient and to understand when it is necessary to change from cure to care [16].

4.5. Financial Needs

A study to evaluate the barriers to provide EOLC in a resource-limited setting conducted by [14], stated that all participants in this study reported that financial needs were the barrier to pediatric EOLC. All staff stated that patients were often unable to pay for prescribed medicines, hospital supplies, laboratory tests, or even food, clothes, and

hospitalization fees. These resource limitations hindered the staff's ability to provide not only basic care but also to provide comfort at the end of life, such as medication for pain or oxygen therapy [14].

4.6. Nurses' Feeling

Providing care for children in a palliative situation, as well as for their families, is a highly demanding and stressful task for nurses, particularly when the health status of the child deteriorates and the care have to be directed toward EOLC [4]. Study conducted by [21], mentioned that nurses discussed struggling with their feelings of ambivalence and sorrow during their experiences of caring for dying pediatric patients. When discussing ambivalence in patient care, nurses explained a sense of doubt as to whether or not the care rendered was appropriate for the situation and sorrow might interfere with help in enhancing parental interactions with the dying pediatric patient and it can hinder the last moments between the dying child and family and becoming a deterrent to providing quality care for the dying pediatric patients [21].

4.7. Aggressive intervention received by the patient

Providing aggressive treatment also described as barriers to providing pediatric end-of-life care [19]. Study conducted by [19], also mentioned that fear of respiratory depression surrounding opiate use at the end of life can inhibit the full transition to a palliative care framework at the end of life. On some circumstances, the medicalisation of care caused in continued aggressive and ongoing treatment, despite an acknowledgement that the child was probable to die and it was identified as a source of frustration, distress and conflict for nurses [17].

4.8. Inadequate hospital facilities

Deficiencies in hospital resources, such as a consistent availability of feeding tubes, blood products, and pain medications, might affect nurses ability to provide care for terminally ill pediatric patients [14]. Another barrier related to inadequate hospital facilities were poor design of units that do not allow for privacy of dying patients or grieving family, a visiting hours that are too restrictive, lack of standard guidelines, and also lack of legal support [19].

5. Conclusion

Nurses enact a crucial role in caring for dying children and the children's families. Overcoming barriers in EOLC provision could greatly improve the quality of end-of-life care for dying children. Therefore, it is necessary to develop a conceptual model to support nurses and health care professionals in providing EOLC for pediatric patients.

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Conflict of Interest

The authors have no conflict of interest to declare

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