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Experience of nurses who work with children with palliative care needs: A mixed-method systematic review

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Review Article

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Abstract

Objective. The importance of palliative care education for nurses has been recognized worldwide. The study aims to explore the experiences of nurses working with children with palliative care needs and to identify any related educational needs.

Methods. The electronic databases of CINAHL, Cochrane, PubMed, OVID, Social Care Online, Web of Science, Scopus, and ProQuest were searched for the period 2000–2015.

Results. Finding revealed that working with children with palliative care needs is an emotionally struggling job for nurses, especially when they try to manage the transition of pediatric patients from curative to palliative care. Staffing level and time constraints comprise a major obstacle in pediatric palliative care. Focusing on invasive treatment and technology in spite of the feelings that it will not improve patients' health status intensifies the feeling of guilt and helplessness for nurses. Finally, nurses asserted the importance of receiving pediatric palliative care education, especially how to communicate with children with palliative care needs and their families.

Significance of results. Further research is recommended with regard to nurses' experience in communication with children with palliative care needs. Nursing education in pediatric palliative care is significantly important, especially how to communicate with children with palliative care needs and their families.

Introduction

It is estimated that 16 out of every 10,000 children and adolescents aged under 19 suffer from life-threatening illnesses and get palliative care services (Cochrane et al., 2007). Although innumerable studies have focused on the prevention and cure of childhood diseases, limited attention has been devoted to end-of-life (EOL) issues for young patients. Nurses have integral roles in the relief of suffering for children and their families. However, they spend the most time with patients and their families, and they may know little about the principles and skills of pediatric EOL care (Gallagher et al., 2012; Peng et al., 2013).

The importance of palliative care education for health care providers has been recognized worldwide. Nursing education for EOL care is essential, because nurses assume the role of patients' advocate and have more contact with patients and their families as compared to other health professionals. As a result, nurses' knowledge, attitudes, and skills are the keys to improve health care outcomes in this field to help patients and families to achieve a higher quality of life (Brooten and Youngblut, 2006). As Virginia Henderson described (1964):

> The unique function of the nurse is to assist the individual, sick or well, in the performance of those activities contributing to health or its recovery (or to a peaceful death) that he would perform unaided if he had the necessary strength, will or knowledge. And to do this in such a way as to help him gain independence as rapidly as possible. [p. 63].

Pediatric palliative patients are cared for not only on palliative specialized units but also at home or non-specialized hospital wards as well as nursing homes. Therefore, it is not only specialized nurses who need contact with the palliative patients but also student nurses and novice nurses have to be able to provide adequate care to them (De Vlieger et al., 2004; Johnston and Smith, 2006). Palliative care is an essential theme in nursing, and its skills are important for both nurses and nursing students at all levels. Patients with life-limiting conditions have a special need for appropriate compassionate support from nurses in addition to maintaining the best possible quality of life during the palliative phase (Johnston and Smith, 2006). Lack of adequate specialized palliative care training or access for training pediatric and neonatal nurses, combined with the difficulties experienced by many health care professionals in communication with patients and families, especially discussing bad news and prognoses with children and parents, contributes to low-quality EOL services (Malloy et al., 2007). Thus, this

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review explores the experiences of nurses working with children with palliative care needs and determines any related educational needs.

Methods

The keywords used for this search are summarized in Table 1. Table 2 presents the inclusion and exclusion criteria specified before starting to search the literature. Only articles published in English were included in this study, which could lead to missing some articles written in other languages. However, as translation is costly and inefficient prior to identifying the utility of a study, and as most medical research worldwide is published in English, only articles written in English are included in this review. The electronic databases of CINAHL, Cochrane, PubMed, OVID, Social Care Online, Web of Science, Scopus, and ProQuest were searched for the period 2000–2015 (Table 3). Thematic analysis and synthesis for each study's findings were performed to identify the major themes. Based on Lucas (Lucas et al., 2007), prominent or recurrent themes for every individual study was followed by an amalgamation of the findings under major headings.

Quality assessment

Multiple critical appraisal tools were used because of the multiple research methodologies utilized in the studies found in the literature. The Joanna Briggs Institute (JBI) tool was used for the evaluation of qualitative studies, as it is the most coherent tool in comparison with both Critical Appraisal Skills Program (CASP) and the Evaluation Tool for Qualitative Studies (ETQS) (Hannes et al., 2010). Three more critical appraisal tools were used: JBI Critical Appraisal Tool for Systematic Review was used to be consistent with the JBI qualitative tool, and the Critical Appraisal of a Survey used by the Center for Evidence-Based Management (CEBM) and the Evaluative Tool for "Mixed Method Study Designs" created by Prof. Long et al. (2002), School of Health Science, University of Leeds. After the exclusion of an additional study that did not report sufficient information about the methodology used, 20 studies were included in this review. Of these 20 studies, 9 were qualitative, 8 were quantitative, 2 were mixed methods, and 1 was a systematic review.

Results and discussion

A total of 8,289 studies were returned after analyzation. The titles and/or abstracts of all the studies were screened for relevance and studies that did not match the inclusion criteria were excluded. The full-text articles were obtained and reviewed for matching the inclusion criteria, whereas 25 duplicate articles were excluded. In the end, 55 papers were reviewed completely and 20 papers were accepted (Figure 1). The research papers were used to extract and tabulate the required data (Table 4).

Emotional distress

Thirteen studies revealed that working with children with palliative care needs was emotionally struggling for health care providers, especially when they try to manage the transition of pediatric patients from curative to palliative care (Costello and Trinder-Brook, 2000; Papadatou et al., 2001, 2002; Yam et al., 2001; Contro et al., 2004; Clarke and Quin, 2007; Epstein, 2008; Lee and Dupree, 2008; Amery et al., 2010; Kain, 2011;Cook et al., 2012; Borhani et al., 2013; Cooper et al., 2013). A study conducted by Yam et al. (2001) revealed that nurses struggle to diminish the emotional suffering that results from the termination of the relationship with infant and parents after the death of the infant. This is the reason nurses try to make distance emotionally from parents and infants. They try to keep themselves busy with physical care to minimize any social interaction or discussion about the infant's condition with parents (Yam et al., 2001). The following nurse's response clarified that:

> When I knew the baby was going to die and could not recover to come back to see us again as other babies did, it was difficult for me to continue our relationship further. I tried to divert my attention to physical care, such as cleansing and turning the infant. I did not take the initiative to talk to the parents. When the parents cried, I did not know how to handle it. [p. 654]

Papadatou et al. (2001) and Li et al. (2002) stated the impact of grieving reaction by exploring the differences in grief reaction between nurses from two cultures, Greek and Chinese. The results showed that 75% of the Chinese nurses reported conscious suppression of feelings, while Greek nurses expressed their sadness more explicitly, such as crying behaviors, despite reporting strong grief reactions after the death of children among nurses from both cultures (Borhani et al., 2013). According to literature, nurses had no training to regard to assess and strengthen their own resources and they were unaware of the supportive tools that could relieve their suffering (Lee and Dupree, 2008; Amery et al., 2010). However, Cook et al. (2012) reported that many nurses used memories to cope with the stressful situations they face. Others use certain words or phrases to describe their experiences to protect the people around them.

A qualitative descriptive research approach was employed by Keenan and Mac Dermott (2016) to identify the experiences of grief by the nurses followed by the death of any child who was under their care. The results showed that limited experience and knowledge tend to make them helpless, whereas the majority of them try their level best to focus on positives after the death of a child in their care. The grief experiences by nurses have not been addressed within the practice setting; therefore, it is necessary to show that nurses respond emotionally to patients' death and experience grief (Khalaf et al., 2017). The experiences of grief among the nurses about emotional labor and death of the patient (child) are part of their work that affects their personal as well as professional lives (Granek et al., 2015).

Another study showed that only 7% of nurses reported avoidance of being involved with patients and their families to protect themselves from emotional suffering. Instead, the majority of them experienced grieving after the death of patients, and they described their responses to loss and grief as being characterized by sadness, depression, disappear, guilt, needing to cry or pray, and withdrawing from daily activities (Papadatou et al., 2001). A study conducted among Iranian nurses reported that they suppress their emotions as a result of their cultural expectations to conceal their feelings. In addition, they feel compelled to hide their emotions, especially if the child's diagnosis is unknown to their families (Borhani et al., 2013). One nurse said:

> … He had two big front teeth and he was tall…I took some days off, when I came back, they said he passed away; I couldn't be convinced at all. He was the first patient I really liked. Then suddenly, he was absent at the time

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Table 1. The keywords used in the systematic search

1. Experience 2. Perception 3. Perspective 4. Meaning 5. Narrative 6. Understanding 7. Attitude 8. 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7	9. Nurse 10. Health care provider 11. Health professional 12. Health team 13. RN 14. 9 OR 10 OR 11 OR 12 OR 13	15. Child 16. Adolescent 17. Teenage 18. Infant 19. Newborn 20. Neonate 21. "Preschool age" 22. "School age" 23. Toddler 24. Juvenile 25. Pediatric 26. Pediatric 27. "Young patient" 28. Childhood 29. 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28	30. Palliative care 31. Life threaten 32. Life limit 33. "End of life" 34. Incurable illness 35. "Terminally ill" 36. Heart failure 37. Liver failure 38. Kidney failure 39. Cystic fibrosis 40. HIV/AIDS 41. Cardiovascular anomalies 42. Extreme prematurity 43. Neuromuscular 44. Neurodegenerative disorders 45. Progressive metabolic disorders 46. Chromosomal abnormalities 47. Advanced metastatic cancer 48. Severe cerebral palsy 49. Genetic disorders 50. Congenital malformations 51. Prematurity 52. Brain injury 53. Spinal cord injury. 54. 30 OR 31 OR 32 OR 33 OR 34 OR 35 OR 36 OR 37 OR 38 OR 39 OR 40 OR 41 OR 42 OR 43 OR 44 OR 45 OR 46 OR 47 OR 48 OR 49 OR 50 OR 51 OR 52 OR 53 OR	55. Educate 56. Knowledge 57. Learn 58. Train 59. Teach 60. Study 61. Coach 62. Tutor 63. 55 OR 56 OR 57 OR 58 OR 59 OR 60 OR 61 OR 62	64. Need 65. Requirement 66. Demand 67. 64 OR 65 OR 66 68. 8 AND 14 AND 29 AND 54 69. 14 AND 29 AND 54 AND 63 AND 67 70. 68 OR 69

> of my arrival to the work. Oh my God, I was really sad. I said I wouldn't even cry for this, it might impact my emotion but I wouldn't cry. But I really got sad then. I do not cry in front of others, but I got really sad for him. No! I did not cry, I rarely cry… [p. 3].

Guilt and helplessness feelings are commonly experienced by nurses who work with dying pediatric patients (Costello and Trinder-Brook, 2000; Papadatou et al., 2001, 2002; Yam et al., 2001; Davies et al., 2008; Borhani et al., 2013). Papadatou et al. (2002) found that 57% of nurses and physicians experienced a sense of powerlessness upon the death of a child patient; they felt that they could have done something more to help the child, despite their knowledge that this would not have been effective. Similarly, Borhani et al. (2013) recruited nurses who participated in the in-depth interviews, who felt that their working efforts are ineffective and they do not believe in the treatment when it results in the death of children. One of the nurses narrated that "No, we don't believe in treatment! We, ourselves, are watching children's death all the time. Ultimately all of them would die anyway" [p. 4].

Some nurses have a feeling of relief from stress after the death of the children, especially if this is happened after a long period of pediatric suffering from disease (Costello and Trinder-Brook, 2000). In summary, emotional distress was a major theme in the literature exploring the experiences of nurses working with dying children. Five studies reported the effects of staffing level on the quality of care for dying children and their families (Costello and Trinder-Brook, 2000; Papadatou et al., 2002; Davies et al., 2008; Kain, 2011; Chen et al., 2013). Nurses feel frustrated as they do not find enough time to spend with child patients and their families, because they have too much work in their department. However, other nurses in one of those two studies appreciated ward work as a means to escape from what they considered as a very stressful (bedside) situation.

Providing palliative care through technology

The nurses feel a sense of helplessness and sadness when they feel that they are unable to help terminally ill infants. This feeling may intensify when they are required to perform painful procedures following doctors' orders, while some of them think that other less intrusive treatments could be more suitable to decrease the suffering of infants (Yam et al., 2001; Lee and Dupree, 2008; Cooper et al., 2013). In addition, nurses experienced moral distress because of using prolonged aggressive treatment, especially in the teaching hospitals because they consider it as an experimental hospital. According to one of the nurses;

> Some of us feel like its experimental because this is a teaching hospital but sometimes it feels like, 'let's try this. Oh, today let's try this.' It feels like we're prolonging the inevitable and when the baby seems like they're suffering, that's when it becomes very difficult. [p. 775]

Chen et al. (2013) stated that 90% of nurses agreed that they went beyond their comfort level by using technological life support. Despite the feelings that it will not improve patients' health status, the nurses feel that the initiation of high-tech support was undertaken (Lee and Dupree, 2008). One nurse stated: "I got paged that they were putting him on ECMO [extra corporeal membrane oxygenation] support, which I knew was going to be the end of his life, and he died shortly thereafter" [p. 988].

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Table 2. Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Papers published in English	Papers not published in English
Quantitative, qualitative, mixed methods, and systematic reviews	Other study designs
Papers conducted in hospital, medical, or hospice centers settings	Papers conducted in community settings
Papers in which the highest proportion of the participants was nurses work with children (under 18) with palliative care needs	Papers in which participants are not nurses or nurses who do not work with children with palliative care needs
Papers which study experience or educational aspects for nurses	Papers which study other aspects of nurses' professional work

Table 3. Database search details for the systematic search

Name of database	No. of hits	Related papers	Extract no.	Title or abstract
CINAHL	1,841	21	4	Title, abstract, keywords
Cochrane	81	1	0	Abstract
PubMed	1,250	5	1	Title
OVID	1,974	34	5	Title, abstract
Social Care Online	218	0	0	Title
Web of Science	2,527	6	1	Title
Scopus	371	7	4	Title
ProQuest	27	9	2	Title
Manual search (specialized journals search, Google Scholar, articles' references search)		7	4	
Total	8,289	90	21	

Facilitating communication between children and families

The most frequent educational need reported by nurses who work with children with palliative care needs was communication skills with children and their families (Yam et al., 2001; Engler et al., 2004; Chen et al., 2013). Nurses faced several challenges with regard to communication with patients or their families, and in many situations, they found themselves being unprepared to act or behave in a proper way. Nurses reported being at a loss for words especially when discussing prognosis issues with dying children and families. One nurse (female, 31 years old) reported that: "When they (children) ask me 'what's my illness? Will I get better?' I don't know what to answer. I feel helpless" [p. 348].

Amery et al. (2010) conducted a mixed-method study to investigate children's palliative care educational needs for the health professional in Uganda. Using the self-rating survey, log book analysis, and focus group, communication with children was found to be the highest educational need reported by 50 health professionals (including 41 nurses). The participants demonstrated difficulties with regard to informing and explaining relevant information to children, including breaking bad news, and dealing with strong feelings or denial reactions. These difficulties were connected with nurses' fear of receiving difficult questions or negative emotions; "[I recognized] the importance of proper explanation and full information… helping the child to have a full insight and be compliant… and the need to use proper communication skills to assess properly… and obtain trust in each other" [p. 149].

Amery's study did not report cultural factors in disclosing poor prognosis to children. Cultural factors affect how much explanation is usually disclosed to children with palliative care needs. It is important to understand whether or not the cultural norms of disclosing disease information to children could exaggerate the challenges faced by nurses when answering children's difficult questions. Therefore, further studies need to be conducted which explain how cultural beliefs could affect the disclosure of information about the disease to children with palliative care needs in order to address the challenges to communication faced by nurses and their relation with children's awareness of their diagnosis or poor prognosis. The nurses are likely to face difficulties in communicating with children and their families during a long hospital stay. Moreover, the communication gap increases during the crisis period like diagnosis, disease relapse, or terminal disease stage (Citak et al., 2013).

The abilities of health professionals to communicate well decrease when pediatric patients are not given any information about their disease (Papadatou et al., 2001, 2002; Citak et al., 2013). Nurses reported that they avoid answering questions that children and families ask as they are well aware of the disease and therapy and they hesitate to provide this information on their behalf. The dominant culture in which palliative care service is provided affects the nurses' fear of answering difficult questions related to poor prognosis. For instance, it is common practice in the Greek culture not to inform children about their diagnosis. Instead, information about poor prognosis and imminent death is communicated by a physician and only to the parents who usually try to adopt a protective approach toward their child (Papadatou et al., 2001, 2002). Therefore, Greek nurses face more difficulties when children who have no awareness about their diagnosis try to ask questions about their diseases and prognosis.

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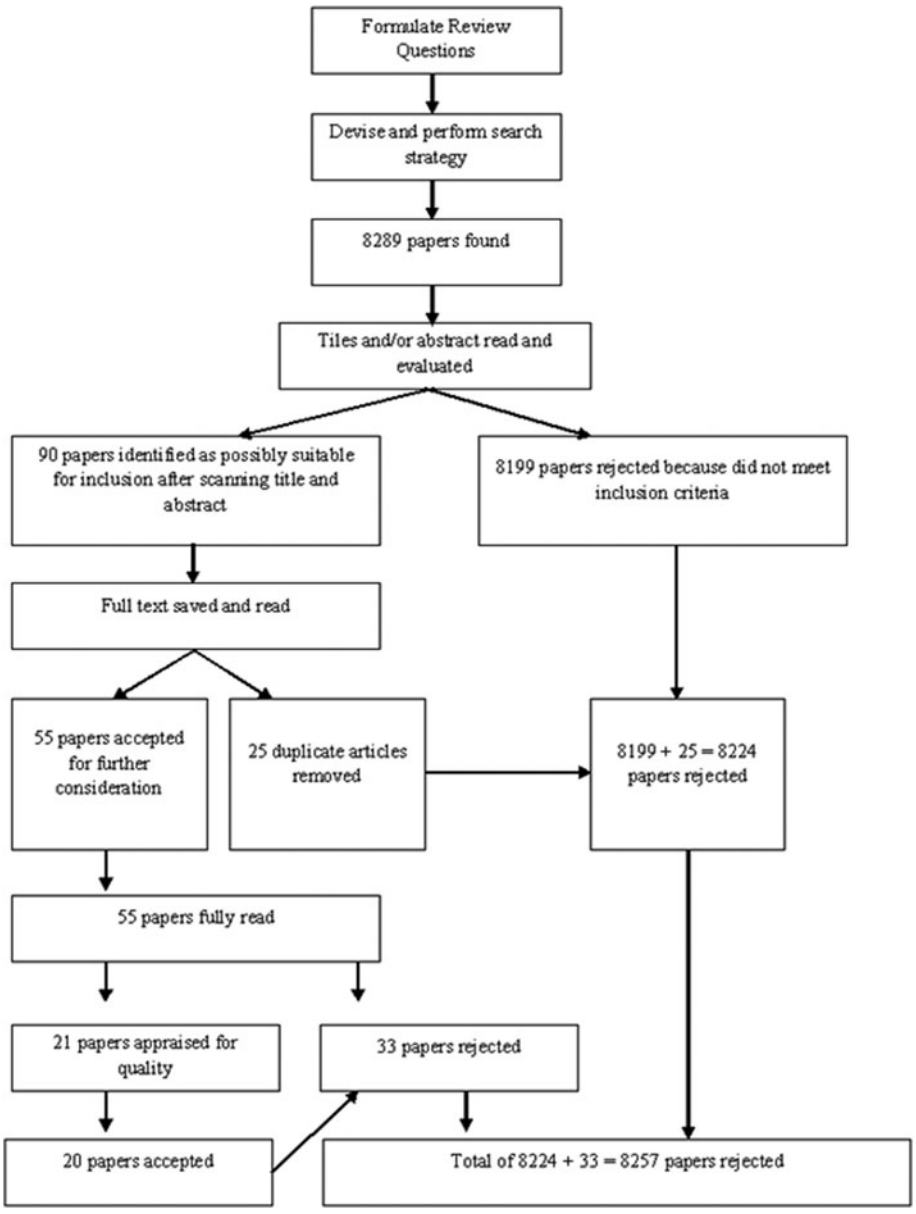


Fig. 1. Search process.

Inadequate skills to overcome family conflicts

Nurses desire to acquire additional communication skills, which help them to deal appropriately especially in critical situations, such as informing families of sudden death, transition from curative to palliative care, and discussing "don't resuscitate" status (Citak et al., 2013).

Nurses reported that they had inadequate helping skills, especially with terminally ill, depressed, and desperate patients, particularly because they did not know how to give hope to those patients. They stated that they felt demotivated when children withdrew themselves from communication as they were in a depressed mood and avoided contact with health care providers (Citak et al., 2013). In addition, Yam et al. (2001) found that most nurses stated that they had inadequate knowledge and expertise with regard to supporting grieving parents. They felt uncomfortable observing parents suffer and they did not know how to behave. The following response is an example:

> Although I have a Bachelor Degree in Nursing, I must admit that my ability in counselling is not good. I tried to comfort the parents, but I found I was just repeating the same words or sentences. I didn't know if I could help the parents in this way. [p. 655]

Two studies included conflict with patients and their families as one communication barrier faced by nurses while working with children with palliative care needs (Citak et al., 2013). According to Citak et al. (2013), nurses relate their communication difficulties to the negative responses given by some families as a result of the disease of their children, which can be expressed in blaming nurses. Nurses relate that to the exhaustion felt by families, their inability to support their child, their attitudes to the disease, and sometimes their exposure to other parents: "They both do not accept their disease and secretly blame us when they have accepted, as if we are the reason for their disease" [p. 5479].

The second reason for conflict reported by nurses in the previous study was the inability to maintain professional boundaries,

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Table 4. Data extraction for the studies included in the systematic review

	Author year Country	Journal	Article title	Aim	Design/methods	Settings	Participants	Reported main findings	Notes and critiques
1	Clarke and Quin (2007) ***Ireland***	*Qualitative Health Research*	Professional carers' experiences of providing a paediatric palliative care service in Ireland	To explore the experience of health professional of providing pediatric palliative care to pediatric with life-limiting conditions	A mixed-method research design	Community-based care agencies and/or hospitals	Clinical nurse managers, pediatricians, clinical nurse specialists, palliative care groups, and medical social workers	The themes include: clarity of definition and complexity of engagement, the emotional cost of providing palliative care and seeking to deliver a palliative care service	The qualitative part of this mixed-method study was presented in this paper. No justifications of not using certain methodological approach
2	Yam et al. (2001) ***China***	*Journal of Clinical Nursing*	Caring for dying infants: Experiences of neonatal intensive care nurses in Hong Kong	To explore the experiences of Hong Kong nurses who work in neonatal unit in terms of caring for dying infants	Semi-structured interviews	SCBU (Special Care Baby Unit) and NICU (Neonatal Intensive Care Unit) of a large teaching hospital in Hong Kong	10 registered nurses	Eight themes emerged: Feeling ambivalent and helpless, providing optimal physical care to the infant, lack of knowledge and counseling skills; providing emotional support to the family; disbelieving; conflicting values in care; protecting emotional self and expressing empathy	Convenient sample. Small sample size recruited from one hospital. No justifications of not using certain methodological approach
3	Chen et al. (2013) ***Taiwan***	*Maternal Child Health Journal*	To explore the neonatal nurses' beliefs and attitudes towards caring for dying neonates in Taiwan	To explore attitudes and beliefs of neonatal nurses who work with dying neonates toward nursing care.	A cross-sectional design	Four NICUs at four medical centers in Taiwan	80 neonatal nurses	Barriers hinder neonatal palliative care: insufficient communication due to the lack of an in-service educational program; parental demands; the lack of available counseling help for neonatal clinicians; inability to express personal opinions towards neonatal palliative care; the technological imperative; insufficient staffing; the lack of unit guidelines for supporting palliative care.	Small sample size Convenient sampling which affects the external validity Sample size has not been calculated based on pre-studies considerations of statistical power.

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4	Papadatou et al. (2002) ***Greece***	*Paediatric Nursing*	Greek nurse and physician grief as a result of caring for children dying of cancer	To explore and compare the grief reactions and experiences of Greek nurses and physicians who provide care to dying children with cancer	A semi-structured interview	Major pediatric oncology units	16 pediatric oncology nurses and 14 oncologists	Two main categories of responses: (a) difficulties related to the dying and death conditions and (b) difficulties related to communication problems faced by children and parents throughout the terminal phase. In both groups, death triggered a sense of helplessness and powerlessness felt by staff as a result of their inability to decrease patient suffering	Inclusion criteria of the sample were not mentioned clearly. No information about reviewing of data analysis by a second researcher (trustworthiness) and the ethical approval process was not reported
5	Cook et al. (2012) ***USA***	*Journal of Paediatric Nursing*	Coping while caring for the dying child: Nurses' experiences in an acute care setting	To understand behaviors and coping mechanisms used by pediatric nurses who care for dying children	Qualitative descriptive design using focus groups	Children's academic center specifically inpatient cardiology unit	17 staff nurses and 5 nurse practitioners	Categories emerged includes boundaries, memories, disconnecting, and labeling	One hospital setting. Working experience was not included in the inclusion criteria as it could affect the experience (reality shock for new graduates)
6	Costello and Trinder-Brook (2000) ***UK***	*Paediatric Nursing*	Children's nurses' experiences of caring for dying children in hospital	To explore the experiences of nurses who care for children who are dying in hospital care settings	Questionnaires, focus group, and individual interviews	Three hospitals in the northwest of England	44 pediatric nurses who had cared for dying children in hospital settings	Themes are: a sense of guilt about the death; coping with the death of a child; death as a sense of relief/failure; the need to support grieving relatives and the influence of organizational factors in death management	Convenient sampling. Small sample size. No information about the statistical analysis of the questionnaire was reported
7	Engler et al. (2004) ***USA***	*American Journal of Critical Care*	Neonatal staff and advanced practice nurses' perceptions of bereavement/ end-of-life care of families of critically ill and/or dying infants	To describe the perceptions of bereavement/ end-of-life care for neonatal nurses	A cross-sectional, study (e-mail survey)	NICUs	190 RNs' and APNs' were randomly recruited from 125 hospitals	Language or cultural differences influenced the involvement with patients' families. A total of 63% indicated that their basic nursing education programs had included content on bereavement and end-of-life care. However, only 42% of them were satisfied	The content of bereavement education they received was not specified whether it is pediatric or adult contents. Response rate was 52%; however, a large sample size, using randomized sampling, will

(*Continued*)

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Table 4. (*Continued.*)

	Author year Country	Journal	Article title	Aim	Design/methods	Settings	Participants	Reported main findings	Notes and critiques
								with the amount of content provided.	increase the control on the confounding factors that could affect the external validity of the findings
8	Kain (2011) ***Australia***	*Neonatal Paediatric and Child Health Nursing*	To explore the barriers to palliative care practice in neonatal nursing: A focus group study	To explore barriers to palliative care practice for nurses who work in neonatal units	Focus groups	Three neonatal intensive care units (NICU)	24 registered nurses who have experience in neonatal intensive care	Major barriers were: inadequate staffing, parental expectations, and unconducive physical environment	Multiple settings. Inclusion criteria clearly stated. Doctoral supervision team were involved to enhance rigor
9	Epstein (2008) ***USA***	*Journal of Perinatology*	End-of-life experiences of nurses and physicians in the newborn intensive care unit	To explore the experiences of physicians' and nurses' who work with newborns who are in the end-of-life stage in an intensive care unit	A hermeneutic phenomenology using semi-structured interviews	One NICU in a mid-Atlantic university hospital	11 physicians and 21 nurses	Major theme was to create the best possible experience for parents. Subthemes include: building relationships, creating memories, and preparing for the EOL	Only one setting (One NICU). However, interviews were made for nurses, physician, and parents (this triangulation helped to clarify the themes and maximize the consistency of the results)
10	Beck Strand and Rawle (2010) ***USA***	*American Journal of Critical Care*	Paediatric nurses' perceptions of obstacles and supportive behaviors in end-of-life care	To determine the perceptions of pediatric intensive care unit with regard to frequencies, sizes, and magnitudes of selected barriers and facilitators' behaviors when providing end-of-life care to pediatric patients	Survey was mailed to the possible participants	PICU nurses who were members of the American Association of Critical Care Nurses (AACN)	1047 nurses	Language barriers and parental discomfort in withholding mechanical ventilation. The highest supportive behavior was giving time alone with the child when he or she has died	Sample was drawn from one specialty nursing organization therefore; the results reflect only those within this organization (AACN). Response rate was 48% which could decrease the internal validity of the study

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11	Davies et al. (2008) ***USA***	*Paediatrics*	Barriers to palliative care for children: perceptions of paediatric health care providers	To explore obstacles to pediatric palliative care experienced by health care providers who care with seriously ill children	Self-reported questionnaires	An academic children's hospital	117 nurses and 81 physicians	Communication barriers and inadequate education in pain management were cited by one-third of the participants. Other barriers include uncertain prognosis, family that does not acknowledge incurable conditions, language barriers, and time constraints	One hospital setting. Response rate is 34% which could affect the internal validity
12	Tubbs-Cooley et al. (2011) ***USA***	*Journal of Palliative Medicine*	Paediatric nurses' individual and group assessments of palliative, end-of-life, and bereavement care	To describe palliative care aims and problems as rated by pediatric nurses	A cross-sectional survey (web-based questionnaire)	A freestanding children's hospital	410 nurses completed the survey (44% response from the 932 eligible nurses)	Goals as rated by nurses include: pain management, quality of life for children, and improving communication. Problems include: lack of opportunity to debrief after a patient's death, uncertainty about the goals of care, and the reluctance of the health care team to discuss hospice with family	Web-based survey could introduce selection bias. Only one hospital. Response rate was 44% which could affect the internal validity especially if the sample was not recruited randomly
13	Cooper et al. (2013) ***Australia***	*Neonatal, Paediatric and Child Health Nursing*	Neonatal palliative care nursing: working with infants on the cusp of life — a thematic review	To identify nurses' experiences of providing palliative care and to identify obstacles to providing this care effectively through analyzing 16 articles	Thematic review analyses	N/A	16 articles	Main findings: nurses felt distressed when they tried to manage the transition from curative to palliative, nurses expressed ambivalence regarding the use of invasive technology. Nurses perceived experience and education as critical factors to deal with the complexities of palliative care	The researcher acknowledged certain limitations of this review like: including studies that have only one setting and including a pilot study. Review included a study in which nurses were not part of the participants as it stated in the inclusion criteria No studies were excluded in spite of the number of limitations they included

(*Continued*)

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Table 4. (*Continued.*)

	Author year Country	Journal	Article title	Aim	Design/methods	Settings	Participants	Reported main findings	Notes and critiques
14	Amery et al. (2010) ***Uganda***	*Journal of Palliative Medicine*	A study into the children's palliative care educational Needs of health professionals in Uganda	To explore the educational needs for health care providers who work in different hospice settings in Uganda	Mixed-method: self-rating survey, log book of problem cases and focus group	Three hospice sites in Uganda	6 doctors, 41 nurses, and 3 clinical officers	Communication with children was rated as the highest educational needs in all phases of the study	No justifications of not using certain methodological approach in the qualitative phase. No information about reviewing data analysis by second researcher (trustworthiness). The inclusion and exclusion criteria were not mentioned. Convenient sampling technique. Small sample size in the quantitative phase
15	Peng et al. (2013) ***Taiwan***	*Nurse Education Today*	The educational needs of neonatal nurses regarding neonatal palliative care	To explore the experiences of neonatal nurses in terms of caring for dying neonates and to assess their educational needs	A cross-sectional survey	Three NICUs at three medical centers	115 nurses	Only 13% indicated that they have received neonatal palliative care education. Pain control was rated by half of the participants as the area in which they most required training	Convenient sampling. Inclusion criteria of the participants were not clearly specified Response rate 92%
16	Gallagher et al. (2012) ***UK***	*International Journal of Palliative Nursing*	A training needs analysis of neonatal and paediatric health care Staff in a tertiary children's hospital	To explore the educational needs of health professionals who work with families with palliative or end-of-life care requirements	Online questionnaire	A tertiary children's hospital in London	111 participants The majority of them were nurses (61%)	93% did not feel that they received enough education in pediatric palliative care, with only 33% reporting they had received any training in palliative care Participants reported having least confidence in their knowledge of the community services that are available and	Response rate was not known because of the duplication on the distribution list which could affect the internal validity. Inclusion criteria of the sample were not clearly mentioned. Sample size was

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								the legal and professional issues that surround palliative care for patients and their families	not specified before the study
17	Papadatou et al. (2001) ***Greece and Hong Kong***	*Cancer Nursing*	Caring for dying children: A comparative study of nurses' experiences in Greece and Hong Kong	To explore the experiences of nurses who work with dying children in oncology and critical care units in Greece and Hong Kong	Semi-structured interviews	Oncology units and intensive care units located in two pediatric hospitals in both Athens and Hong Kong	24 Chinese nurses and 39 Greek nurses	Main results: feeling of helplessness when caring for a dying patient. Difficulties in communication with the child and parents during the terminal phase of the disease. Nurses reported significant rewards when they care for chronically and acutely ill children	No justifications of not using certain methodological approach. Ethical approval process was not mentioned
18	Contro et al. (2004) ***USA***	*Paediatrics*	Hospital staff and family perspectives regarding quality of paediatric palliative care	To assess the needs of staff members which precede the improvement of pediatric palliative care program	Staff survey, family interviews	Children's Hospital at Stanford	446 staff members including nurses	Feeling inexperienced in communicating with pediatric patients and families, half of the nurses reported feeling inexperienced in symptom management and 30% of the nurses reported feeling inexperienced pain management	Single study setting. Sampling errors and selection bias which could affect the generalizability of the results. Response rate was not determined as the number of the participants who have received the online survey was unknown
19	Borhani et al. (2013) ***Iran***	*Iranian Journal of Nursing and Midwifery Research*	Lived experiences of paediatric oncology nurses in Iran	To explore the experiences of Iranian nurses who care for children with cancer	In-depth, unstructured interviews with open-ended questions	A hospital in a metropolitan city of Iran	Pediatric oncology nurses (exactly number not mentioned)	Five themes included attachment, supportive care, trying to repress feelings, feeling of helplessness, and the need for being supported	No justifications of not using certain methodological approach. Ethical consideration was not mentioned. No information of how the rigor of this study was achieved. Reflexivity was not reported

(*Continued*)

Table 4. (*Continued.*)

	Author year Country	Journal	Article title	Aim	Design/methods	Settings	Participants	Reported main findings	Notes and critiques
20	Lee and Dupree (2008) ***USA***	*Journal of Palliative Medicine*	Staff experiences with end-of-life care in the paediatric intensive care unit	To describe the experiences of pediatric intensive care unit health professionals who care for children who are dying	Semi-structured interviews	A large, multidisciplinary PICU	29 staff members. Participants included physicians, nurses, and psychosocial support personnel	The major themes were communication importance; accommodating the wishes of others despite personal preferences; ambiguity about the use of technology; sadness and emotional support	One setting (PICU) Credibility achieved through second verification of the transcribed audiotapes. Inclusion criteria was not clearly defined

as a result of the long period that patients and their families stay in hospital. Consequently, the relationship between nurses and patients' families, particularly children's mothers, tends to shift toward a nonprofessional direction. The following is an example of that:

> Professionalism shifts, for example, they stay at the hospital for four months. The mothers get some ideas that we are friends. Sometimes I am shocked by their behaviour; they try to join us, they abuse close relations. We cannot make contact with them if we avoid from behaving in such a way, there is a fine line… [p. 5479]

In the previous study, however, it seems that there is some ambiguity about how the inability to maintain professional boundaries will negatively alter communication between nurses and child patients and their families; in other words, the previous study did not clarify the negative consequences that could result from moving toward social relationship with families, which could require further investigation. Finally, dealing with demanding and manipulating parents is another communication difficulty experienced by Chinese nurses who felt that they were unprepared to deal with such situations (Papadatou et al., 2001). Providing good quality life to the dying patients is considered as a national priority as it provides guidelines to care for the patients and give them a good death. An important role is played by the nurses in delivering EOL care. Their efforts should be acknowledged on the basis of symptoms of palliation and social context of dying. A study explored the perspectives of qualified nurses towards the EOL education, and the results clarified that preparing nurses is a challenging task for the educators, although EOL care in nurse training is significantly emphasized (Cavaye and Watts, 2012). In the life story of an individual, the dying experience is carried forever among the individuals who received care from nurses. The individuals making their career as a nurse need to have proper knowledge about end-of-life nursing education. Moreover, they need to be comfortable with dying and are capable of reflecting their feelings regarding end-of-life care (D'antonio, 2017).

Conclusion

The results introduced a preliminary understanding of nurses' experiences with regard to working with children with palliative care needs. Several gaps were found in the literature that justifies the need for further studies. One of the major issues found to be in need for further investigation is the role of culture on the grief reaction and the coping mechanism expressed by nurses. In addition, the effect of staffing level and time pressure on the quality of nursing care provided also needs to be investigated to reveal whether time pressure is a real obstacle faced by nurses in providing compassionate care or whether it is a defense mechanism they use to escape from stressful situations. Moreover, nurses' negative attitudes toward using technology and invasive procedures in the EOL period require more explanation in terms of whether or not their attitudes are affected by other factors, such as their skills and abilities to work with these machines, and the extra workloads these machines add. Furthermore, more studies need to be conducted to assess the educational needs (especially the communication skills) for health care professionals working in pediatric palliative care as it is underpresented by literature in comparison with adult palliative care.

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References

Amery JM, Rose CJ, Byarugaba C, *et al.* (2010) A study into the children's palliative care educational needs of health professionals in Uganda. *Journal of Palliative Medicine* **13**, 147–153.

Beck Strand and Rawle (2010) Paediatric nurses' perceptions of obstacles and supportive behaviors in end-of-life care. *American Journal of Critical Care* **19**, 543–52.

Borhani F, Abbaszadeh A, Mohsenpour M, *et al.* (2013) Lived experiences of pediatric oncology nurses in Iran. *Iranian Journal of Nursing and Midwifery Research* **18**, 349.

Brooten D and Youngblut JM (2006) Nurse dose as a concept. *Journal of Nursing Scholarship* **38**, 94–99.

Cavaye J and Watts JH (2012) End-of-life education in the pre-registration nursing curriculum: Patient, carer, nurse and student perspectives. *Journal of Research in Nursing* **17**(4), 317–326.

Chen CH, Huang LC, Liu HL, *et al.* (2013) To explore the neonatal nurses' beliefs and attitudes towards caring for dying neonates in Taiwan. *Maternal and Child Health Journal* **17**, 1793–1801.

Citak EA, Toruner EK and Gunes NB (2013) Exploring communication difficulties in pediatric hematology: Oncology nurses. *Asian Pacific Journal of Cancer Prevention* **14**(9), 5477–5482.

Clarke J and Quin S (2007) Professional carers' experiences of providing a pediatric palliative care service in Ireland. *Qualitative Health Research* **17**, 1219–1231.

Cochrane H, Liyanage S and Nantambi R (2007) *Palliative Care Statistics for Children and Young Adults. Health and Care Partnerships Analysis*. London: Department of Health.

Contro NA, Larson J, Scofield S, *et al.* (2004) Hospital staff and family perspectives regarding quality of pediatric palliative care. *Pediatrics* **114**, 1248–1252.

Cook KA, Mott S, Lawrence P, *et al.* (2012) Coping while caring for the dying child: Nurses' experiences in an acute care setting. *Journal of Pediatric Nursing* **27**(4), e11–e21. doi:10.1016/j.pedn.2011.05.010

Cooper H, Cuthbertson L and Fleming S (2013) Neonatal palliative care nursing: Working with infants on the cusp of life – a thematic review. *Neonatal, Paediatric and Child Health Nursing* **16**, 2.

Costello J and Trinder-Brook A (2000) Children's nurses' experiences of caring for dying children in hospital. *Paediatric Care* **12**, 28–32.

D'antonio J (2017) End-of-life nursing care and education: End-of-life nursing education past and present. *Journal of Christian Nursing* **34**(1), 34–38.

Davies B, Sehring SA, Partridge JC, *et al.* (2008) Barriers to palliative care for children: Perceptions of pediatric health care providers. *Pediatrics* **121**, 282–288.

De Vlieger M, Gorchs N, Larkin PJ, *et al.* (2004) Palliative nurse education: Towards a common language. *Palliative Medicine* **18**(5), 401–403.

Engler AJ, Cusson RM, Brockett RT, *et al.* (2004) Neonatal staff and advanced practice nurses' perceptions of bereavement/end-of-life care of families of critically ill and/or dying infants. *American Journal of Critical Care* **13**(6), 489–498.

Epstein EG (2008) End-of-life experiences of nurses and physicians in the newborn intensive care unit. *Journal of Perinatology* **28**, 771–778.

Gallagher K, Cass H, Black R, *et al.* (2012) A training needs analysis of neonatal and paediatric health-care staff in a tertiary children's hospital. *International Journal of Palliative Nursing* **18**(4), 197–201.

Granek L, Bartels U, Scheinemann K, *et al.* (2015) Grief reactions and impact of patient death on pediatric oncologists. *Pediatric Blood & Cancer* **62**(1), 134–142.

Hannes K, Lockwood C and Pearson A (2010) A comparative analysis of three online appraisal instruments' ability to assess validity in qualitative research. *Qualitative Health Research* **20**, 1736–1743.

Henderson V (1964) The nature of nursing. *The American Journal of Nursing* **64**(8), 62–68.

Johnston B and Smith LN (2006) Nurses' and patients' perceptions of expert palliative nursing care. *Journal of Advanced Nursing* **54**, 700–709. doi:10.1111/j.1365-2648.2006.03857.x

Kain V (2011) Exploring the barriers to palliative care practice in neonatal nursing: A focus group study. *Neonatal, Paediatric and Child Health Nursing* **14**, 9.

Keenan P and Mac Dermott C (2016) How nurses grieve for children who die in their care. *Learning Disability Practice* **19**(3), 16.

Khalaf IA, Al-Dweik G, Abu-Snieneh H, *et al.* (2017) Nurses' experiences of grief following patient death: A qualitative approach. *Journal of Holistic Nursing* **36**(3), 228–240.

Lee KJ and Dupree CY (2008) Staff experiences with end-of-life care in the pediatric intensive care unit. *Journal of Palliative Medicine* **11**, 986–990. doi:10.1089/jpm.2007.0283

Li SP, Chan CW and Lee DT (2002) Helpfulness of nursing actions to suddenly bereaved family members in an accident and emergency setting in Hong Kong. *Journal of Advanced Nursing* **40**, 170–180.

Long A, Godfrey M, Randall T, *et al.* (2002) Developing evidence based social care policy and practice. Part 3: feasibility of undertaking systematic reviews in social care. *Project Report, University of Leeds, Nuffield Institute for Health, Leeds*.

Lucas PJ, Baird J, Arai L, *et al.* (2007) Worked examples of alternative methods for the synthesis of qualitative and quantitative research in systematic reviews. *BMC Medical Research Methodology* **7**, 4.

Malloy P, Sumner E, Virani R, *et al.* (2007) End-of-life nursing education consortium for pediatric palliative care (ELNEC-PPC). *MCN: The American Journal of Maternal/Child Nursing* **32**, 298–302.

Papadatou D, Martinson IM and Chung PM (2001) Caring for dying children: A comparative study of nurses' experiences in Greece and Hong Kong. *Cancer Nursing* **24**, 402–412.

Papadatou D, Bellali T, Papazoglou I, *et al.* (2002) Greek nurse and physician grief as a result of caring for children dying of cancer. *Pediatric Nursing* **28**(4), 345–353.

Peng NH, Chen CH, Huang LC, *et al.* (2013) The educational needs of neonatal nurses regarding neonatal palliative care. *Nurse Education Today* **33**(12), 1506–1510.

Tubbs-Cooley HL, Santucci G, Kang TI, *et al.* (2011) Pediatric nurses' individual and group assessments of palliative, end-of-life, and bereavement care. *Journal of Palliative Medicine* **14**(5), 631–637.

Yam B, Rossiter JC and Cheung K (2001) Caring for dying infants: Experiences of neonatal intensive care nurses in Hong Kong. *Journal of Clinical Nursing* **10**, 651–659.

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