



## Nurses' experiences of providing palliative care for children with life-limiting conditions: an integrative review

Reid, B., & Brogan, P. (2024). Nurses' experiences of providing palliative care for children with life-limiting conditions: an integrative review. *International Journal of Palliative Nursing*, 30(5), 212-224.  
<https://doi.org/10.12968/ijpn.2024.30.5.212>

[Link to publication record in Ulster University Research Portal](#)

**Published in:**  
International Journal of Palliative Nursing

**Publication Status:**  
Published (in print/issue): 02/05/2024

**DOI:**  
[10.12968/ijpn.2024.30.5.212](https://doi.org/10.12968/ijpn.2024.30.5.212)

**Document Version**  
Author Accepted version

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**Background:** Paediatric palliative care has evolved in response to the increased prevalence of children who have been diagnosed with life-limiting conditions. Nursing care is a fundamental aspect of PCC and understanding nurses' experiences is imperative to the provision and development of quality holistic child-centred services.

**Aim:** To review nurses' experiences of providing palliative care for children with life-limiting conditions.

**Search Methods:** A systematic database search of the Cumulative Index to Nursing and Allied Health Literature (CINAHL) Complete, Ovid Medline and Scopus was undertaken. Key words consisted of "palliative care" or "terminal care" or "dying" or "end of life care" and children\* or paediatric\* or pediatric\* and "nurs\* experience\*" or "nurs\* view\*" or "nurs\* perspective\*" or "nurs\* feeling\*". Inclusion criteria included peer-reviewed studies published between 2016-2023 in the English language.

**Findings:** A thematic approach was adopted with the eleven papers selected for the review and each study critically analysed to identify three recurring themes. The themes included: 'A broken wreck', 'Makes a life worth living' and 'Challenges in doing 100%'. Findings point to mixed feelings among nurses in providing paediatric palliative care and suggest that nurses experience emotional distress when caring for dying children. With appropriate supports and inspiration from their paediatric patients, nurses are determined to provide a 'good death' for the children in their care. Nevertheless, the perceived lack of knowledge and experience, communication struggles and personal dilemmas can be predisposing factors in triggering negative experiences among nurses when providing palliative care for children with life-limiting conditions.

**Recommendations:** Education and policy development is required to meet the practice needs and support the emotional needs of nurses engaged in PCC. Further research is required to generate PCC evidence-based nursing interventions. In doing so, high quality PCC practice will be promoted, thereby ensuring high quality PPC for the children and their families.

# Nurses' experiences of providing palliative care for children with life-limiting conditions: **an integrative review**

## Introduction

Advances in medicine, technology and care interventions have contributed to an increasing prevalence of children living with complex and life limiting conditions (Mitchell *et al.* 2019). Life-limiting conditions are those for which there is no reasonable hope of cure and that will eventually lead to the child's death (Fraser and Parslow, 2018). Approximately 21 million children worldwide are living with a life-limiting condition (Marston *et al.* 2018), with the most common diagnoses encompassing genetic or chromosomal syndromes, cancer, neurologic and metabolic aetiologies (Grossoehme *et al.* 2020; Bergsträsser 2018). Some children may not receive a formal diagnosis. In view of the life-limiting nature of these conditions, care for these children must integrate curative and palliative approaches with an emphasis on quality of life (Graham and Robinson 2005). Paediatric palliative care (PPC) is an evolving field for which available resources are insufficient to meet the needs to children with life-limiting conditions (Marston *et al.* 2018).

The World Health Organisation (WHO 2020) describe palliative care as an approach to caring for patients and their families facing the effects of a life-threatening illness by addressing their physical, spiritual, psychological and social needs. PPC seeks to achieve similar goals to those of adult palliative care, enhancing an individual's quality of life and alleviating suffering. However, PPC differs from adult palliative care in that it may extend for months or even years and the approach to care is child-centred (whilst acknowledging the importance of parents and families) (Ford *et al.* 2018). Furthermore, End-of-life (EOL) care is described as care provided within the last year

of life, in particular the last few months or directly preceding death as it ensures the greatest comfort and dignity of individuals and their families (National Institute for Health and Care Excellence 2019). Nevertheless, with considerable diversity in conditions and generally unknown trajectories distinct needs and circumstances for children emerge (Chong *et al.* 2018). WHO (2018) state PPC is appropriate early during a child's illness in combination with other treatments to prolong the child's life. Additionally, Mitchell *et al.* (2019) voice that approximately 7 million children worldwide with life-limiting illness would benefit from early implementation of PPC services. However, it is stated that globally 65% of countries have no recognised children's palliative care (CPC) services (Connor *et al.* 2017).

**Nurses encounter patients experiencing life-limiting illnesses in all healthcare settings and nurses' experiences of PCC may differ depending upon the environment they practice in.** Regardless of setting, nurses tend to have the most contact with their patients and play a key role in alleviating suffering and providing holistic child-centred palliative care as they are purposefully placed to recognise the needs of children and to facilitate informed decision-making (Nursing and Midwifery Council 2018; Sekse *et al.* 2018). However, research states nurses feel hesitant about providing palliative care to children as they have inadequate knowledge and training necessary for the effectual provision of PPC (Chan *et al.* 2019; Atout 2020). Nurses subject to the suffering of paediatric patients and their families experience emotions of grief, moral distress, anger, sorrow and vexation. These elicited feelings can cause compassion fatigue which is a factor related to burn-out among nurses which can ultimately lead to nurses resigning (Erikson and Davies 2017).

Therefore, the following integrative review aims to critically explore the views and experiences of nurses providing palliative care to children with life-limiting conditions

and provide recommendations to aid future practice. An integrative review was chosen as it offers valuable insights into existing research on a topic and provides a firm basis from which to abstract themes from several studies and integrate them into broader forms of knowledge that can propose future research directions on how the subject can be improved (Cronin and George 2020). This was extremely important for the selected topic due to the lack of a comprehensive amalgamation of existing literature.

## **Method**

### **Search strategy**

To aid this literature review a database search of the Cumulative Index to Nursing and Allied Health Literature (CINAHL) Complete, Ovid Medline and Scopus were conducted. The CINAHL database is argued to be important when carrying out a literature review regarding topics in nursing as its scope of research is more profound than other databases (Wright *et al.* 2015). The key search words comprised of “palliative care” or “terminal care” or “dying” or “end of life care” and children\* or paediatric\* or pediatric\* and “nurs\* experience\*” or “nurs\* view\*” or “nurs\* perspective\*” or “nurs\* feeling\*”. Several limiters were used to refine the searches. The publication year was restricted to 2016-2023. The search beginning in 2016 was chosen due to the release of “The Children’s Palliative Care Strategy- A strategy for Children’s Palliative and End-of-life Care 2016-2026” by the Department of Health and NICE guidelines regarding “end-of-life care for infants, children and young people with life-limiting conditions: planning and management” both in 2016. These strategic policies and guideline were introduced with the aim to provide high quality, safe and effective palliative care to children. Additional limiters included academic journals and

English language. Table 1 summarises the selected databases, limiters, hits and selected sources provides an overview of the searches. The search strategy is an integral component of a literature review as it allows the readers to interpret, assess and analyse the literature before carrying out the review (Parahoo 2014).

## **Study selection**

To guide the identification of relevant literature the PRISMA guidelines (Liberati *et al.* 2009) were consulted. The PRISMA flow chart (Figure1) shows the steps taken to select the overall number of sources to be used in the review. Initially a total of 61 sources were discovered by searching the three databases. Afterwards duplicates were removed, 24 sources remained. The papers title and abstract were screened, and 9 sources excluded as they contained irrelevant material or were focused on doctors' experiences. The full text articles were then scanned with 10 sources being eliminated as the articles focus on adult palliative care or a specific condition such as cancer. Table 2 provides a summary of the inclusion and exclusion criteria used when selecting relevant studies. After exclusion, five articles from the database searches remained and were included in the literature review. Additionally, the 'snowball method' was utilised which entails selecting studies cited by the articles found in searches. It is acclaimed that electronic searching sometimes does not present all published material and hand searching was also carried out by looking at reference lists (Perez-Bret *et al.* 2016). From undertaking these methods, eight articles were chosen for eligibility. However, two articles were excluded as they focused on adult palliative care, the remaining six were included in the review.

## **Data extraction and analysis**

Data extraction is the means of extracting data from primary research into any standardized form. It provides the basis for the results and conclusion of a systematic review while improving validity as it minimises bias and gives reliable findings (Mathes *et al.* 2017). Table 3 details the data extraction process to include author, location, aim/purpose, design, sample, method of data collection, main findings/results and strengths and limitations of the chosen papers from the database searches. A thematic approach was undertaken to critique the chosen literature. The thematic approach is widely used when conducting research as it aids in identifying themes within current literature, it involves repeatedly examining the literature and summarising key aspects through a coding process (Nowell *et al.* 2017). A descriptive coding process was used to organise and analyse the findings. The initial codes were then organised into tentative themes by the first author (PB) and then discussed confirmed by consensus with the second author (BR). The three main themes identified for the review were: 'A broken wreck', 'Makes a life worth living' and 'challenges in doing 100%'. Table 4 categorises the themes according to the relevant studies.

## **Critical Review of the Literature**

The selected articles for the review were predominately qualitative studies, using approaches such as phenomenology, to aid in understanding the experiences of nurses (Bloomer *et al.* 2015; Hendricks-Ferguson *et al.* 2015; Bloomer *et al.* 2016; Stayer and Lockhart 2016; Curcio 2017; McConnell and Porter 2017; Nurse and Price 2016; Muskat *et al.* 2020; Devitt and O'Hara 2021; Bassola *et al.* 2023). Regarding the

quality of included studies, the hierarchy of evidence pyramid deems qualitative studies as low quality, due to their sample size. However, a critiquing framework by Parahoo (2014) voice that the majority of research can be of value regardless of the sample studied. Furthermore, (n=1) study within the review was a cross-sectional quantitative, ranked as the second highest quality within the pyramid (Kaye *et al.* 2019). The majority of included studies were assessed as being of good quality using the Critical Appraisal Skills Programme (CASP 2018) qualitative study checklist. The majority of the sources (n=8) used a variety of focus groups and individual or semi-structured interviews to collect data (Bloomer *et al.* 2015; Hendricks-Ferguson *et al.* 2015; Bloomer *et al.* 2016; Stayer and Lockhart 2016; Curcio 2017; McConnell and Porter 2017; Nurse and Price 2016; Muskat *et al.* 2020; Devitt and O'Hara 2021; Bassola *et al.* 2023). Additionally, (n=1) utilised cross-sectional surveys with Likert-style scales (Kaye *et al.* 2019). As suggested by CASP (2018), studies identified the methods utilised to enhance trustworthiness and credibility such as rigorous data analysis processes, clear statements of findings and respondent validation of findings (Bloomer *et al.* 2016; Stayer and Lockhart 2016; McConnell and Porter 2017; Muskat *et al.* 2020; Bassola *et al.* 2023). All studies had small sample sizes. However, the purpose of qualitative research is to provide insight and understanding rather than generalisable results. In addition, (n=5) reported limited studies on the topic, contributing to knowledge and valuable to literature (Bloomer *et al.* 2015; Hendricks-Ferguson *et al.* 2015; Nurse and Price 2016; Curcio 2017; Kaye *et al.* 2019).

With respect to populations studied, (n=8) concentrated solely on nurses (Bloomer *et al.* 2015; Hendricks-Ferguson *et al.* 2015; Bloomer *et al.* 2016; Stayer and Lockhart 2016; Curcio 2017; Kaye *et al.* 2019; Devitt and O'Hara 2021; Bassola *et al.* 2023), (n=1) centred on nursing students (Nurse and Price 2016) and (n=2) focused on a mix



of health care professionals, for instance, physicians, healthcare assistants, social workers and nurses (McConnell and Porter 2017; Muskat *et al.* 2020). The studies included within the review differ in geographical locations. The studies were carried out in the United States (n=4) (Hendricks-Ferguson *et al.* 2015; Stayer and Lockhart 2016; Curcio 2017; Kaye *et al.* 2019), Northern Ireland (n=2) (Nurse and Price 2016; McConnell and Porter 2017), Australia (n=2) (Bloomer *et al.* 2015; Bloomer *et al.* 2016), Ireland (n=1) (Devitt and O'Hara 2021) and Italy (n=) (Bassola *et al.* 2023). One study did not specify a location (Muskat *et al.* 2020).

## **Findings**

The three themes generated were not discrete but rather connected and interwoven, providing an insight into nurses' experiences of PCC. 'Makes a live worth living' demonstrated how nurses sought to provide a quality child-centred service but faced 'challenges in doing 100%' and often perceived themselves as 'a broken wreck' due to the emotional burden of PCC. **Despite diverse practice settings and the associated expectation that, for example, the PCC experiences of generalist nurses might differ from nurses working in children's hospice settings, similar themes emerged across all settings.**

### **'A broken wreck'**

During a nurse's career, they provide care to sick and suffering individuals and those nearing the end of life. However, caring for a child who is dying is emotionally demanding for nurses because it is recognised as contrary to the way in which the natural process of life should transpire (Curcio 2017). In a hermeneutic phenomenological study carried out by Stayer and Lockhart (2016) exploring the perspectives of 12 paediatric intensive care unit (PICU) nurses through face-face

interviews it was found that nurses providing palliative care to dying children found the experience emotionally exhausting. The majority of the nurses within the study voiced feelings of frustration, sorrow and helplessness. These feelings were suggested to arise from nurses often feeling they were causing unnecessary pain to the child and finding it overwhelming to observe the families watch their child deteriorate and in time pass away (Stayer and Lockhart (2016). A qualitative phenomenological study by Curcio (2017) using semi-structured interviews to explore the experience of nine nurses providing end-of-life care to paediatrics portrays similar findings. Caring for dying children was emotionally distressing as children were often exposed to drawn-out procedures in the hope of prolonging their life although the nurses knew the outcome for the child and the effect this would have on their parents as 'It's someone's baby...They're not supposed to die" (Curcio 2017 p10). Devitt and O'Hara (2021) explored the experiences of 14 paediatric ward-based nurses and reported how nurses felt that 'no one else gets it' when a child dies. Consequently, they did not discuss the impact of such emotive events outside of the clinical environment despite the associated stress affecting their personal lives.

Contrary to the views of the previous authors, a qualitative mixed methods study conducted by Bloomer *et al.* (2015) through focus groups sought to discover the perspectives of 22 PICU and neonatal intensive care unit (NICU) nurses providing palliative care to paediatrics and found that nurses felt as a child's death neared maintaining life prolonging procedures were appropriate. Although the nurses voice 'aggressive' interventions, such as some oncology treatments, caused feelings of anger and tension among the nurses, the purpose of the continuance of treatments was not to cure the child but to allow time for their families to come to terms with the situation of which the nurses felt was of great significance in supporting the family unit.

However, this is conflicting with the beliefs of nurses to prevent the pain and suffering of those in their care and that simple comfort measures and effective pain management should be advocated for to ensure the wellbeing of the child (Hendricks-Ferguson *et al.* 2015; Stayer and Lockhart 2016; Curcio 2017). Additionally, a qualitative study conducted by Bloomer *et al.* (2016) using focus groups and individual interviews to gain the perspectives of 28 nurses across a PICU and NICU providing care to children at the end-of-life suggested that activities such as taking handprints and photographs is an effectual way of preparing the family for the child's death.

Several studies express that frequent, long periods of hospitalisation facilitated the creation of bonds among the nurses, child and family (Hendricks-Ferguson 2015; Stayer and Lockhart 2016; Curcio 2017; Muskat *et al.* 2020). Therefore, witnessing the death of a child causes vast personal suffering for nurses followed by feelings of regret, guilt and desolation (Curcio 2017), particularly if it was the nurses first paediatric death encounter (Hendricks-Ferguson 2015). A descriptive qualitative study carried out by Hendricks-Ferguson *et al.* (2015) exploring the experiences of 14 novice nurses through focus groups found that nurses experience feelings of guilt and regret as they repeatedly thought about if they could have possibly done more for the child and their family. Furthermore, the nurses stated that, when a child is nearing the end-of-life, it cannot always be predicted and when it occurred, they were often unprepared causing feelings of discomfort in working with dying children (Hendricks-Ferguson 2015). Comparably, a qualitative paper by Muskat *et al.* (2020), who carried out semi-structured interviews with 25 health care professionals, including doctors (n=8), nurses (n=8) and social workers (n=9) discovered that when a child's condition was worsening it was difficult to accept the fact that they were powerless in controlling the outcome which had significant professional and emotional impacts. This appeared to be

attributable to the fact that the nurses felt they could personally relate with the situation as they usually compared the dying child to their own children, who they would not give up on, causing intense personal and professional dilemmas for nurses. (Stayer and Lockhart 2016; Curcio 2017; Muskat *et al.* 2020).

### **‘Makes a life worth living’**

Although the care of a child at the end-of-life is an immense responsibility accompanied by distressing emotions and difficult decisions, it also has positive personal and professional impacts on nurses (Muskat *et al.* 2020). The qualitative study by Muskat *et al.* (2020) found that the health care professionals who participated in the research were appreciative of the personal growth after caring for a child at the end-of-life. The participants of the study voiced that paediatric palliative care continually impacts their perspective on life. The nurses described how after the death of a child, they often thought about the important aspects of their life and the significance of appreciating a ‘good life’ as there’s more serious things going on in the world than small little everyday ‘nuisances’ (Muskat *et al.* 2020 p110). Comparably, the qualitative study by Curcio (2017) observed that nurses who cared for dying children were inspired by their patients who were at the most vulnerable moments of life to identify what parts of their life were extremely important to them. Furthermore, observing the strength and determination possessed by the children, particularly when they were against all odds and recovered from critical situations, influenced nurses to be strong and resilient (Curcio 2017).

However, Muskat *et al.* (2020) states that caring for children at the end-of-life sometimes has negative effects on a nurse’s outlook on life. Several nurses within the study stated that seeing children suffering from an illness where death was probable

often generates feelings of fear and anxiety when thinking about having children of their own. Similar to Devitt and O'Hara (2021), Muskat *et al.* (2020, p109) found that some nurses felt that it negatively impacted personal relationships as when they returned home after a difficult day at work, they found themselves 'snappy' and 'short-tempered' as they could not discuss their feelings with anyone outside work. Studies state that the development of individual-level support from healthcare organisations, such as the integration of debriefing into normal practice, mindfulness centred support therapy, would be beneficial to safeguard the psychological wellbeing of staff (McConnell and Porter 2017; Muskat *et al.* 2020; Devitt and O'Hara 2021).

A qualitative study carried out by McConnell and Porter (2017) with the use of focus groups and individual interviews in the hope of obtaining the experiences of 15 health care professionals, including nurses (n=11) and healthcare assistants (n=3), delivering end-of-life care to children reported that the most positive experience was 'making a difference' in one of the most challenging situations a family could face, prompting professional satisfaction (McConnell and Porter 2017). Likewise, the study by Muskat *et al.* (2020) found that healthcare professionals define their careers as a privilege and experience a sense of professional fulfilment by providing high-quality end-of-life care to paediatrics. In addition, the participants of the study stated that providing palliative care to paediatrics offered new learning opportunities due to the high complexity and unpredictability of PPC. The staff also noted that knowing they had managed a child's pain effectively and reduced the suffering of the family was an extremely rewarding role (Muskat *et al.* 2020). Contrarily, Hendricks-Ferguson *et al.* (2015) found that the rapid, complex events that occurred with PPC is innately unfamiliar to newly qualified nurses of which they feel they do not have the skills or knowledge required to act independently and thus, experience feelings of guilt and regret in not fulfilling their

professional role effectively. Accordingly, it is suggested that novice nurses would benefit from mentorship to aid in preparing them to intervene effectively and to appreciate the professional fulfilment providing PCC can bring as it is an environment where everyone is 'still learning' (Hendricks-Ferguson *et al.* 2015 p32).

### **'Challenges in doing 100%'**

The main goal for nurses when providing palliative care to children with life-limiting conditions is to go above and beyond their professional role to deliver high quality and compassionate care to the child and their families (Stayer and Lockhart 2016). However, several studies state recurring challenges faced by nurses in the provision of effective palliative care for children as: struggling with communication and insufficient knowledge and training (Bloomer *et al.* (2015); Hendricks-Ferguson *et al.* (2015); McConnell and Porter (2017); Nurse and Price (2017); Stayer and Lockhart (2016); Kaye *et al.* (2019).

With respect to communication, Hendricks-Ferguson (2015) suggested that struggles with communication are due to uncertainty regarding when to initiate and engage in conversations about end-of-life care with the child and their family and nurses often feeling uncomfortable in doing so. This study suggests nurses often simplify communication with the child and their family as they feel the child's condition is deteriorating but are uncertain of the child and their parent's knowledge and acceptance of the situation. For instance, Hendricks-Ferguson *et al.* (2015) stated that nurses often found themselves feeling anxious and reluctant to respond when parents of the child would ask how they felt about the child's condition or when the child themselves required help to comprehend what other healthcare professionals had discussed. The nurses within the study implied that this was due to the fact that

although they sensed the end was near, they perceived themselves to be inexperienced in recognising the signs of a child approaching the end of life and often found themselves being somewhat dishonest as they felt family struggles may occur such as avoidance as a coping strategy. Additionally, this was further mentioned in the study conducted by Stayer and Lockhart (2016), who discovered that PICU nurses frequently avoided being realistic and truthful with the child and their families as they did not want to deprive them from maintaining hope.

Conversely, research carried out by Bloomer *et al.* (2015) reported that keeping the child and their family at the core of all communications was of utmost importance to the nurses. The finding suggested that beginning and engaging in conversations with the child and their families obtained clarification on their perspective regarding the individual's condition, aided them in coming to terms with the situation and enabled the nurses to build relationships with child and their family. However, Bloomer *et al.* (2015) found nurses often struggled in communicating with the child and their families when physicians would carry on with aggressive treatments and interventions even though the child was probable to die. Furthermore, Stayer and Lockhart (2016 p355) voiced that nurses often felt it 'wasn't their place' to begin conversations with families about ending treatments. The continuance of these interventions caused frustration and distress among the nurses as they felt the child and families should be provided with the opportunity to discuss and prepare for the impending death. Bassola *et al.*'s (2023) study of 27 paediatric and neonatal intensive care nurses further found that nurses felt a sense of frustration that they were not always listened to when they attempted to contribute to the medical team's decision-making processes. Hendricks-Ferguson *et al.* (2015) also stated that the nurses felt doctors were hesitant in discussing the inevitable with the child and their family and frequently did not engage

in conversations which discouraged treatment and acknowledged the child's prognosis, thereby leaving nurses to face the difficult conversations alone of which they tended to be insincere during or completely avoidant of. Furthermore, the provision of training in end-of-life communication skills were stated in several studies, involving talking with the family, delivering bad news regarding prognosis and discussing treatment choices (McConnell and Porter 2017; Nurse and Price (2017); Kaye *et al.* 2019).

Concerning insufficient knowledge and training, a study by Nurse and Price (2017) with the aim of gaining the perspectives of 12 junior neonatal nurses via focus groups found that the nurses perceived themselves as lacking knowledge and experience in providing effectual palliative care to infants. These concerns appeared to be caused by the lack of children requiring palliative care, failure to detect if a child's condition was deteriorating and managing their symptoms appropriately. Additionally, the nurses voiced they frequently evaded chances to gain experience assuming that the support of senior staff would be absent. The nurses also stressed that they had not received specialist palliative care training (Nurse and Price 2017). Also, within the study conducted by McConnell and Porter (2017), nurses suggested that the most challenging aspect of providing care to the child was achieving the correct combination of medication to relieve the child's symptoms when nearing the end-of-life. Further, a quantitative study by Kaye *et al.* (2019) developed a cross-sectional survey to evaluate 1366 nurses' experiences in the provision of paediatric palliative care across 71 hospices and discovered similar findings to that of Nurse and Price (2017). Of the 279 nurses who responded it was revealed that 80.3% of nurses rarely provide EOL care to paediatrics, no formal training was provided to 89.9% and 78.8% had very little experience in assessing or managing symptoms. As a result of this, almost half of the



participants expressed that they felt very uncomfortable in providing palliative care to children as they've "only got one chance to get it right" (Kaye *et al.* 2019 p247). Similarly, acute care paediatric nurses in Devitt and O'Hara's (2021) study pointed to the scarcity of training in PCC nursing.

Kaye *et al.* (2019) and Nurse and Price (2017) highlight the provision of sufficient paediatric specific palliative care training and education to be the most significant challenge in providing end-of-life care to children. Several nurses within the study conducted by McConnell and Porter (2017) acknowledged the opportunity to attend regular training sessions and sensed the benefit this would bring to the quality of care provided. In addition, it allowed the junior staff to mix with more experienced nurses which was valuable in alleviating fears and anxieties regarding end-of-life concerns. The paper also identified that utilising senior staff is an extremely cost-effective method of training. Similarly, nurses in Bassola *et al.*'s (2023) study sought practical and emotional support from other nurses and senior clinical staff to cope with the uncertainties and stress of PCC. Nurses in this study and that of Nurse and Price (2017) suggest the implementation of debriefing as essential when delivering care to dying children as it allows nurses to voice their feelings and discover methods to manage their emotions. McConnell and Porter (2017) supports this as nurses felt official debriefing aided them in gaining support from senior staff enabling them to feel more comfortable in the provision of care. Additionally, Nurse and Price (2017) recommend the application of a checklist to practice giving novice nurses a feeling of security when caring for children at the end-of-life as it is believed to dissuade thoughts of lacking knowledge and experience.

## **Recommendations for Research, Education, Practice and Policy**

There are several recommendations for developing future research, education, practice and policy following this literature review. Firstly, further research is necessary to gain a comprehensive insight into the experience of nurses providing palliative care to children with life-limiting conditions and to develop evidence-based nursing interventions that might enhance the quality of PCC. Focus areas comprise of coping abilities and grief strategies of nurses, nurses' attitudes towards providing PPC, barriers associated with effective end-of-life communication and the views of family/caregivers of PPC to advance insights of strengths and weaknesses which may otherwise be overlooked. Furthermore, the conduction of studies regarding current nurse education surrounding PPC is essential to guide the training and competency needs of future undergraduate nurses. Concerning education, training is constantly highlighted as essential for nurses and other healthcare professionals providing PPC to equip them with necessary skills and knowledge to aid in fostering positive attitudes and confidence in delivering effective end-of-life care. There is a need to improve undergraduate and postgraduate nursing curricula to include PCC at the earliest possible stage of a nurse's career. Despite the uniformity of findings, learning opportunities need to be tailored to meet the specific needs of nurses in the different settings where these children are encountered, as their needs constantly change. In-depth exercises including advance care planning, end-of-life communication skills and self-care may be beneficial to nurses providing PPC. Importantly, supports such as mentorship for novice nurses and the integration of debriefing need to be made available to nurses to help build resilience, enhance emotional intelligence, and facilitate the processing of experiences and emotions, thereby enhancing the quality of PCC and bringing benefits to nurses' personal lives (Rodríguez-Rey *et al.* 2019).

With regards to practice, the findings of the review may influence the consideration of guidance to assist nurses with PPC care goals and processes, such as the National Hospice and Palliative Care Organization's (2022) *Standards of Practice for Pediatric Palliative Care* that seek to enhance effective identification of and response to the palliative care needs to children in the United States, encompassing diverse disease trajectories. Finally, respecting future policy, it is possible the review could contribute to the development of policies regarding the provision of PPC in healthcare. The policies may include guidelines focused on the training and educating requirements of undergraduate nurses and standards of care for registered healthcare professionals to follow in practice. In addition, the policies could influence the development of designated areas within hospitals for dying children and their families to spend their last moments together in private.

## **Conclusion**

The aim of this review was to explore the experiences of nurses providing palliative care needs to children with life-limiting conditions. To conclude, the critical analysis of the 9 selected studies from the three database searches and several other methods reveals that the experience of nurses providing end-of-life care to children tend to be varied, though, three key recurrent themes emerged. The findings of the literature review concludes that nurses experience emotional distress when caring for dying children. However, with the aid of various support strategies and inspiration from their paediatric patients, are determined to provide a 'good death' for the children in their care. Furthermore, promoting feelings of personal and professional satisfaction in doing so. However, it is vital that nurses balance the relationship between their professional and personal lives to ensure their own wellbeing and the provision of high-quality end-of-life care to their patients. However, the perceived lack of knowledge and

experience, communication struggles and personal dilemmas can be prominent factors in triggering negative experiences among healthcare staff when providing end-of-life care to children.

This review demonstrates the need for further research to aid in the understanding of the attitudes and educational needs of nurses in providing end-of-life care to children, which potentially could result in the development of PPC specific policies and educational curriculums for nurses and other healthcare professionals. Moreover, research gaining insights into the experiences of families and caregivers of children at the end-of-life would be beneficial to practice as it offers additional viewpoints and highlights strengths and weaknesses that can often be missed. In summary, the findings of the review will be valuable in expanding knowledge among nurses in ensuring effective, high-quality PPC.

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