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BMJ Open Voice of the nurse in paediatric intensive care: a scoping review

Kate Masterson (1), 1,2 Michael Connolly, 1 Denise Alexander, 1 Maria Brenner 1

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ABSTRACT

Objectives The objective was to explore how the voice of the nurse in paediatric intensive care units (PICU) is portraved in the literature.

Design Scoping review using the six-step scoping review framework outlined by Arksev and O'Mallev.

Data sources PubMed, Nursing (OVID), Medline (OVID). CINHAL (EBSCO), SCOPUS and Web of Science online databases. The initial search was conducted in June 2020 and was repeated in January 2023.

Eligibility criteria The review included publications in English; published since 2010 in peer-reviewed journals; papers identified nurses in the population studied and conducted in PICU.

Data extraction and synthesis The papers were screened by abstract and subsequently by reading the full text by two independent reviewers. The literature was imported into the software program NVivo V.12 for thematic analysis.

Results The scoping review identified 53 articles for inclusion. While the value of seeking the voice of the nurse has been identified explicitly in other healthcare contexts, it has only been identified indirectly in PICU. Four main themes emerged from the data: the voice of the nurse in the organisation of PICU, caring for children in PICU, as a healthcare professional, and communication in PICU. Conclusion While this literature suggests many facets of the complex role of the nurse, including partnership with

families and advocating for patients, the limited literature on care delivery reduces the capacity to fully understand the voice of the nurse at key junctions of care. Further research is needed on the voice of the nurse in PICU to illuminate the barriers and enablers for nurses using their voices during decision-making.

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¹School of Nursing, Midwifery and Health Systems, University College Dublin, Dublin, Ireland ²Paediatric Intensive Care Unit. Murdoch Children's Research Institute, Parkville, Victoria, Australia

Correspondence to

Kate Masterson: kate.masterson@ucdconnect.ie

INTRODUCTION

The concept of voice is discussed in many within healthcare literature, focusing on research participant perspectives to inform and improve clinical practice, education and policy and to identify future research needs. In the context of this review, the term 'voice' pertains to the perspectives shared by nurses. The presence of the nursing voice in research facilitates nurses to share their experiences and perspectives on areas of importance to them.^{2 3} In the literature, the nursing voice is commonly associated with the nurses role in advocacy and autonomy. 4-6 Research exploring nursing engagement in

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ To the best of our knowledge, this is the first scoping review exploring the voice of the nurse in paediatric intensive care unit (PICU).
- ⇒ This review highlighted key areas of issues impacting on the voice of the nurse in PICU including adaptions in communication, listening to family's needs and advocating for the child's comfort.
- ⇒ It included broad search terms leading to wide range of results; however, there may be articles missed if they did not use the key terms.
- ⇒ Grey literature was not included so may have excluded unpublished literature on the topic.
- ⇒ This review protocol was not registered prior to conducting the review.

organisational change highlights that the absence of the voice of the nurse, and associated powerlessness can impact patients due to power imbalances in the workplace. In paediatrics, nurses are the healthcare professionals with the most contact with families **a** and are thus best positioned to support family presence and participation in care decisions. Despite the pivotal role nurses play in care provision and communicating with families, their voices are under-represented in the scientific literature on children's nursing, specifically within the paediatric intensive care unit (PICU). In this context, voice of the nurse focuses on the perspectives, experiences and insights of the PICU nurse within the published literature.

A scoping review was selected to explore the voice of the nurse in PICU as it offers a means to review evidence and identify research gaps where little research is available. This review will examine how the voice of the nurse in the PICU is portrayed in the literature. It will explore where the voice of the nurse is present from a PICU perspective, why it was sought, what it is saying and identify areas where the voice of the nurse is under-represented or absent. This includes context and focus of the review paper and the key findings that emerge from the literature. A better understanding of the voice of



Table 1 Application of six-step scoping review framework		
Scoping review step	Application	
Stage 1: identifying the research question	This review focused on the research question 'How is the voice of the nurse in PICU portrayed in the literature?'.	
Stage 2: identifying relevant studies	The initial search strategy involved broad terms focusing on any literature involving the nurse in PICU, using the population 'nursing', concept 'voice of' and context 'PICU'. The search was conducted using PubMed, Nursing (OVID), Medline (OVID), CINHAL (EBSCO), SCOPUS and Web of Science online databases.	
Stage 3: study selection	Studies were included if they were published in English, published since 2010, identified nurses in the population and were set in PICU. Research from a variety of countries was included. Any research that described care of paediatric critical care patients was evaluated, including care in of children in mixed adult and paediatric intensive care units due to the high level of critical care provision in these settings. On review of the findings, a decision was made to include only qualitative literature to allow for unconstricted exploration of the voice of the nurse. Literature that was in a setting other than PICU, published in a language other than English and if the voice of the nurse could not be identified was excluded. Comments, editorials and reviews were also excluded.	
Stage 4: charting the data	Each included paper was evaluated to identify the context in which the voice of the nurse was depicted, and related themes were extracted by reviewing the paper findings and identifying key insights related to the voice of the nurse. Themes were extracted and imported to NVivo for thematic analysis.	
Stage 5: collating, summarising and reporting the results.	Key themes are presented in this paper and full summary is in online supplemental table 1.	
Step 6: consultation (optional)	The key stakeholders in this review are PICU nurses. No additional nurses were consulted in this review as they were part of the review team.	
Adapted from Arksey and O'Malley.9		

the nurse in PICU has the potential to highlight nurses' viewpoint on specific care needs of children and families in PICU and affords an insight into their perspectives of working in the PICU environment.

PICU, paediatric intensive care unit.

Objective

To explore how the voice of the nurse in PICU is portrayed in the scientific literature.

METHODS

This review followed the six-step scoping review framework, outlined in the seminal work of Arksey and O'Malley and further developed by Levac et al. 9 10 The application of this framework is summarised in table 1. The initial search strategy involved broad terms focusing on literature involving the nurse in PICU, using the population 'nursing', concept 'voice of' and context 'PICU'. The search terms are outlined in table 2. The search was conducted using PubMed, Nursing (OVID), Medline (OVID), CINHAL (EBSCO), SCOPUS and Web of Science online databases. Studies were included in the initial screening if they met the inclusion criteria: publication in English; published since 2010 in peer-reviewed journals; papers identified nurses in the population studied and conducted in PICU. Research from a variety of countries was included due to the similar processes of care delivery internationally in PICU. Any research that described care

of paediatric critical care patients was evaluated. Where perspectives of parents or multiple healthcare professions are included in the literature, only the voice of the nurse was extracted unless otherwise stated. On review of the findings, a decision was made to include only qualitative literature to allow for unrestricted exploration of the voice of the nurse. While quantitative research can offer insights

Table 2 Search terms			
	Keywords		
Population 'nursing'	Nurs*		
Concept 'voice of'	Advocac* OR power* OR autonom* OR leaders* OR collaboration OR "decision mak*" OR "decision-mak*" OR clinical-decision-mak* OR "best interests decision*" OR best-interests-decision* OR Conflict* OR Nurse-doctor-relations* OR "Nurse doctor relationship*" OR "MDT relationship*" OR "Multi-disciplinary team* relations*" OR "Health professional relation*" OR "multi-disciplin* team relations*" OR "Medical Decision-Mak*" OR "Medical Decision Mak*" OR voice* OR influence OR impact*		
Context 'PICU'	Critical care OR ICU OR intensive care unit OR Intensive care OR PICU OR paediatric		

intensive care OR paediatric intensive care unit

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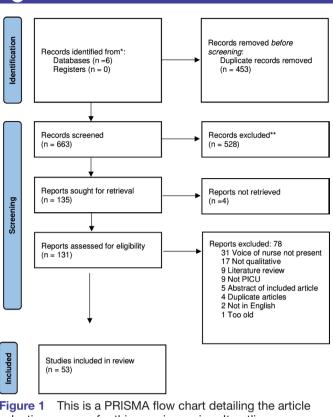


Figure 1 This is a PRISMA flow chart detailing the article selection process for this scoping review. It outlines databased revied (n=6), duplicates removed (n=453), records screened (n=664), excluded in abstract review (n=529), reviewed for full text (n=135), reports not retrieved (n=4), excluded in full text (n=78) and included in the final analysis (n=53). Adopted from Page *et al.* ⁶⁴ For more information, visit: http://www.prisma-statement.org/. PICU, paediatric intensive care unit; PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses. *PubMed, Nursing (OVID), Medline (OVID), CINHAL (EBSCO), SCOPUS and Web of Science online databases. **Excluded in abstract screening.

into a concept, it is restricted by predefined variables and research tools aimed at extracting numerical data to better understand the concept. Qualitative research also allows for the exploration of complex phenomena and supports the emergence of nuances that contribute to a better understanding of the topic. 11 12 Identified papers were imported into the screening tool Covidence. The papers were screened by abstract and subsequently by reading the full text. Findings were discussed with MB and DA for agreement that the papers met the inclusion and exclusion criteria. The selection process is outlined in figure 1. The initial search was conducted in June 2020 and was repeated in January 2023. The literature was imported into the software program NVivo V.12 for thematic analysis. Literature was coded to extract focus of study, key findings and rationale for inclusion of voice of the nurse. NVivo supports the classification and visualisation of themes facilitating the analysis of large quantities of literature. 13

Table 3 General characteristics of the au	Number (n=53)
	Number (II-55)
Sample	
Nurses	30 (56%)
Nurses and healthcare staff	10 (19%)
Nurses and parents	4 (7.5%)
Nurses, healthcare staff and parents	9 (16.5%)
Methods	
Individual interviews	31 (58%)
Interviews and questionnaires	1 (2%)
Interviews and focus groups	7 (13%)
Interviews and observation	7 (13%)
Interviews and simulation observation	1 (2%)
Focus groups	4 (8%)
Observation clinical meetings and survey	2 (4%)
Country	
USA	16 (30%)
Canada	8 (15%)
Europe (including the UK)	15 (28%)
South America	5 (10%)
Australia	4 (7.5%)
Asia	4 (7.5%)
Multicountry	1 (2%)
Location	
Single PICU	40 (75%)
Single hospital PICU and NICU	5 (9.5%)
Multiple PICUs	3 (6%)
NICU, Neonatal Intensive Care Unit; PICU, pae care unit.	ediatric intensive

Findings

The scoping review identified 53 articles for inclusion. The general characteristics of the articles are presented in table 3 and the contexts of the research highlighting the area of focus are presented in table 4. Most studies were conducted in a single PICU; however, some were conducted in both PICU and Neonatal Intensive Care Unit (NICU) with findings combined under the heading nursing perspective. This was attributed to the homogeneous nursing skill set and acuity in some hospitals within their PICU and NICU. Review of the included literature identified four key themes with these contexts that portray the voice of the nurse in PICU, some articles depicted more than one theme. The next sections will discuss each theme including the rationale for seeking the voice of the nurse and key findings.

Voice of the nurse in the organisation of care in the PICU

The research presenting the voice of the nurse in the organisation of care is centred around the model of

Table 4 Contexts of findings		
Context	Reference	
Families and patients in PICU	Baird et al ¹⁴ 24; Butler et al ²² ; Coats et al ¹⁵ ; Denis-Larocque et al ²³ ; Felipin et al ¹⁶ ; Frechette et al ²⁰ ; Geoghegan et al ⁴⁶ ; González-Gil et al ¹⁹ ; Greenway et al ⁶⁵ , Park and Oh ²¹ ; Vance et al ¹⁸ ; Walter et al ⁵³ ; Watson and October ⁵²	
EOL in PICU	Birchley et al ⁵¹ ; Bloomer et al 2015, ²⁵ 2016; ³¹ Carnevale et al ^{29 55} ; Dopson and Long-Sutehall ⁵⁴ ; Gagnon and Kunyk ³⁰ ; Henao-Castaño and Quiñonez-Mora, 2019; ²⁸ Kahveci et al ⁵⁶ ; Lima et al ⁶⁶ ; Medeiros et al ² ; Mesukko et al ²⁶ ; Meyer et al ⁶⁷ ; Meyer, ⁶⁸ ; Michelson et al ⁵⁷ , Michelson et al ⁵⁸ ; Mitchell and Dale ²⁷ ; Nilson et al ³ ; Poompan et al ³² ; Stayer and Lockhart ⁴⁷	
Healthcare delivery	Bower et al^{38} ; Craske et al^{37} ; De Weerd et al^{17} ; Deja et al^{40} ; Ji et al^{69} ; LaFond et $al^{33 \ 34}$; Mattsson et al^{36} ; Soares et al^{70} ; Schults et al^{41} ; Zheng et al^{39}	
Nurse as a healthcare professional	Buckley et al ⁴⁸ ; Burton et al ⁴⁵ ; Foglia et al ⁴³ ; Frechette et al ⁴² ; Mahon ⁴⁴ ; van den Bos-Boon et al. ⁷¹ ; Wei et al ⁴⁹	
EOL, End-of-life; PICU, paediatric intensive care unit.		

family centred care (FCC). This promotes care provision centred around the needs of the family unit aiming to improve communication and minimise disruption to family life as result of hospitalisation. ^{14–16} ¹⁷ The purpose of seeking the voice of the nurse in the context of FCC was attributed to exploring the barriers in implementing FCC particularly focusing on involving families with care delivery and communication with families. ^{15–18} Nurses highlighted that failure to involve families in care provision can result in increased stress for families, thus the need for gaining an understanding of the nursing experience to support better care provision. ⁸¹⁸

From a nursing management perspective, the voice of the nurse described FCC as an ideal model of both parental presence and participation in care, however, in reality, it was not always possible to implement due to its dependence on individual nursing support. 18 The delivery of FCC was described as healthcare professionals giving families a plan of care which aims to manage care delivery. 18 However, these plans were predominantly medically focused and provided only limited descriptions of nursing care plans, thus limiting the nursing voice. This contradicts the essence of FCC, to work with the family to plan care. While nurses supported FCC, they described barriers and enablers including visiting hours and care planning.¹⁵ 16 Challenges included families interrupting care with extensive questioning and increased directive involvement for children admitted for prolonged periods. The nurses suggested that these behaviours resulted in a need to split their time between families and the child, particularly when they felt that the child should be a priority. 15 González-Gil et al also noted that there was an increased parental desire to include siblings in PICU visitation, despite a lack of protocol to support it.¹⁹

Baird *et al* described the existence of explicit rules in PICU including forbidding eating and drinking at the bedside and implicit rules facilitating ward routine and care priorities, which defined expectations of parental behaviour. ¹⁴ Nurses identified their role as rule enforcers, monitoring parental behaviour at the bedside. ²⁰ As a result, they became pseudogatekeepers, regulating the activity

that happens in this environment, such as restricting visitors and enforcing rules. The concept of nurses acting as gatekeepers regulating parental behaviours was identified frequently in the literature but it was not clear where the nurses voice is present in creating these regulations. Park and Oh focused specifically on the partnership between nurses and mothers in PICU; nurses described it as an unequal partnership due to medical knowledge of nursing staff.²¹ As a result, nurses frequently 'managed' parents by limiting information given to reduce anxiety for parents and limiting participation if they felt parental presence impeded clinical care. Similarly, Felipin et alsuggested that the process of enabling parental involvement with care is a process of facilitation and negotiation. ¹⁶ However, this controlled parental involvement in care was not always perceived as negative, as it encouraged parents to engage in care provision when they were reluctant to do so.²² As parents developed skills and knowledge related to their child's condition, nurses encouraged their increasing participation in care provision. 16 This may coincide with a reduction in acuity of care as nurses have more time to support family involvement. However, this facilitation of involvement was limited to the day-to-day care provision as medical teams acted as gatekeepers to involvement in higher-level decisions and information provision.

Voice of the nurse providing care in PICU

This theme portrays the voice of the nurse caring for children with complex needs, caring for children at Endof-life (EOL) and providing clinical care in PICU. The paediatric chronically critically ill (PCCI) patient presents unique challenges in care, particularly for nurses. Multiple studies explored parental views, however, there were few studies capturing the voice of the nurse. Nurse's perspectives were sought to better understand care delivery in this population. Nurses describe the unique requirements of caring for chronically ill children in PICU, and the adjustment required to create a collaborative response as the parent is perceived as 'expert'. ²³ Baird *et al* explored this further during interviews of nurses and family members on continuity of care; a concept where a set list of nurses

cared for the child. Nurses recognised the importance of families in providing continuity; however, they also voiced that delivering this care impacted skill maintenance and their well-being.²⁴

Death and providing care at EOL were identified as part of working in PICU, these can occur suddenly or be expected.²⁵ The terms EOL and palliation were often used interchangeably but within this context focused on care as the child transition to comfort care. Understanding the voice of the nurse was highlighted as a factor in improving care as the clinical team transitions from cure to caring at the EOL.²⁶ Mitchell and Dale identified the lack of recognition of a child's illness as life-limiting as the biggest barrier to initiating the discussion of palliation. 27 28 These discussions on palliation facilitate a redirection of care focused on the comfort of the child rather than interventions to prolong life.²⁶ Nurses identified themselves as the health profession who recognised deterioration of children most frequently.²⁷ ²⁹ They felt that this early recognition contributed to a 'good' or dignified death, resulting in reduced distress for families and staff as families have more time to prepare for death. Nurses suggested that delayed decision-making impacted dignity at EOL, in particular when a 'wait and see' approached was taken, however, were not always involved in this process.³⁰ Bloomer et al found that the nursing role changed when care was redirected towards palliation, nurses increased their focus on the family and created opportunities for them to be with their child.³¹ Nurses frequently valued continuity of care in this context despite not always supporting it.^{2 32}

Overall, there was limited research describing the voice of the nurse in clinical care; however, this may be due to the qualitative focus of the search strategy. The findings predominantly focused on the voice of the nurse in the context of pain and comfort. Nurses described their understanding of pain assessment as incorporating vital and behavioural signs of the child, they used their clinical judgement rather than patient-reported scores to define pain levels. 17 33-35 Nurses highlighted that many existing paediatric pain tools, including verbal scales, were not suitable for PICU because of the child's conscious state despite the recommendation to use them as best practice. In this context, nurses made their decisions regarding pain based on their clinical experience, despite this not being best practice. Closely linked to pain, Mattsson et al explored nursing perspectives of withdrawing from sedation.³⁶ They faced the challenge of balancing patients' well-being with requirements of the unit to wean the patient from sedation and discharge them from PICU. Craske et al described nursing experience as a key factor in the assessment of withdrawal from sedation, though it was further enhanced by continuity of care.³⁷

In other areas of care delivery, Bower et al sought nurses' experience of decision-making during medication administration, noting that nurses demonstrated a need to acknowledge interruptions despite the potential impact on their task. 38 Two further studies explored views of research interventions noting nursing involvement in research planning impacted their engagement with the projects. 39 40 An Australian study explored nursing experiences of suctioning practices in PICU. 41 Nurses identified their experience as a contributing factor in making clinical decisions related to suctioning despite limited evidence to support practice.

Voice of the nurse as a healthcare professional

The nursing voice was also present in exploring factors **v** that cause nurses to both stay and leave PICU. Central to these factors is the concept of professional identity for PICU nurses. This was identified as a factor that influenced nurses' satisfaction with working in PICU and this ξ concept influenced their intent to leave. 42 Nurses voiced & a negative personal impact of carring for carring for carring to c a negative personal impact of caring for children who are from caring for children they described as high acuity. 42 This drive for obtaining clinical skills to care for highacuity children was portrayed as a central factor in a PICU nurse's identity. Foglia et al explored the concept of staff retention among PICU nurses further. Nurses identified the need for a certain level of stress (eustress) in the PICU environment, but many nurses expressed concerns over significant stress when they had insufficient resources to provide ideal standard of care which had a detrimental effect on their own well-being. 43 Mahon noted that this contributed to nurses' likelihood to stay in PICU as they become expert in PICU nursing. 44 This coincided with an evolution in communication and knowledge that allowed them to be perceived as experts and thus equalising their relationships with medical staff resulting in increased contribution to discussions.

Burton et al found that nurses felt they were negatively impacted when they felt team and parent barriers affected their ability to provide care that reflects their own personal values. 45 This included when the nurse felt the child had a poor quality of life. Gagnon and Kunyk also highlighted that nurses were impacted by their burden of knowledge, the information they have as an insider but unable to share it with families. ³⁰ Geoghegan et al described the impact of caring for children who will not recover as an important contributing factor to moral distress in PICU, although they also noted that developing attachment to these children had a positive effect on their well-being. 46 Stayer and Lockhart noted that there was increased distress for the nurses if the child had a lifelong oillness leading to death, rather than death occurring after of a shorter illness. 47 Burn-out was also prevalent in PICU nurses, with most nurses experiencing burn-out at some point although it is difficult to self-identify. 48 Burn-out was impacted, both positively and negatively, by relationships with staff and patient families, challenging patients and related work opportunities. PICU nurses also suggested that they experience burnout differently to other hospital staff due to their unique role in critical care. Wei et al explored strategies to reduce burnout and distress in medical and nursing staff and noted that finding meaning

in work renews the nurse's sense of purpose and increases resilience. 49

Voice of the nurse in communication in PICU

Overall, the literature lacks a clear depiction of the nurse's voice in communication and in decision-making. It was predominantly evaluated as part of broader research exploring communication in PICU, most frequently at EOL. Communication with families and medical staff presented in two domains: in the formal family meeting and informal discussions at the bedside. The role of the nurse in communication was portrayed as an 'in-between' role between families and medical teams.²⁹ Though, Michelson et al suggested that the nurses primarily identify their role as that of family supporter and advocate, not as communicator.⁵⁰ The concept of gatekeeping was evident in communication with families.²² While nurses felt that families were kept well informed, they also felt that there was a limit on the information families needed to know. By controlling this information, they hoped to reduce stress and burden on the parents. Nurses described their role in informing families as reiterating the primary information given by medical teams. Other literature suggests that nurses often introduced 'snippets' of information to allow parents time to process, which suggests the nurses employ tactics to increase parental involvement in communication.⁵¹ Within the formal family meeting format, nurses' identified their role to support efficient communication, to advocate and provide emotional support for families, however, they were frequently absent from meetings and even when present were predominantly silent. 52 53 Similarly at EOL, research highlighted the need for nursing presence at these family meetings during palliative and EOL care discussions to support continuity of care at the bedside. 26 Nurses described their role as advantageous in providing this care as they know the child better than other health professionals and can advocate for the child when enabled to do so. This role of advocate, family supporter and providing comfort also existed when preparing a child for organ donation.⁵⁴ However, competing clinical demands do not always allow the nurse to be present at the meetings.

While many studies suggested that shared decisionmaking occurred, there was a significant variation in the nurses' participation in this process impacted by many factors including context and patient. Carnevale et al explored decision-making to sustain life, noting that physicians felt that nurses should not be responsible for making decisions related to the possibility of death.⁵⁵ Similarly, Kahveci et al described physicians as the primary decision-maker, making decisions on treatment and then informing families of their decisions rather than a shared decision-making process.⁵⁶ Nurses acknowledged their role in the team particularly their relationship with families; however, they felt it was not their place to make decisions. ⁵⁶ Despite this nurses suggested that while they felt they did not have a responsibility in decision-making, they had a responsibility in care delivery.²⁹ Nurses raised

concerns that they struggled to deliver this care when they felt that the care was too invasive and their views on this were not valued. Nurses suggested that they could offer a significant contribution to discussions as they know the family best but felt they are typically excluded from the discussion or that their opinions were not considered, and consequently felt their contribution was undervalued. Nurses believed that their input can lead to greater consistency in decision-making and ensure the child and families 'best interests' are considered.

The literature also identified the silence of the nurse at key points of care. This has the potential to impact both optimal care delivery and the well-being of the nurses. Silence was directly identified at multiple points of care both through the absence of the nurse and even when present their reluctance to voice concerns. In family meetings, nurses described being uncomfortable speaking and feeling they needed permission to speak. ^{29 52} On the scant occasions that the nurse's voice was present during family meetings, they used their expert knowledge to support children and families, but frequently chose to provide care over attending meetings, limiting their ability to be heard in that context. This was highlighted by the nurses' perceived inability to advocate and support families due to their absence in meetings due to the competing demands at the bedside. ^{29 57}

DISCUSSION

While the value of seeking the voice of the nurse has been identified explicitly in other healthcare contexts through exploring the value of nurses' voice in contributing to better care; it has only been identified indirectly in PICU exploring the value of nurses' voice in contributing to through nurse's participation in research on other topics. This review portrayed the voice of the nurse within that literature. Significantly, nurses emphasised that participating in research allowed them to reflect on their 2 professional practice in a context where their voice was otherwise unheard.³ The review found that much of the literature was focused on organisation of care, in particular, FCC and on caring for certain populations of children including those with complex needs and at EOL. It also reviewed literature exploring the perspective of the nurse as a healthcare professional which highlighted the factors that define professional identify for nurses in PICU including a desire to care for acutely unwell children. The review identified common elements that mapped across all themes and were evident in communication and decision-making in PICU. This included the complexities of care provision in PICU and its impact on PICU nurses, challenges in communicating in PICU and adaptions made to support communication. Exploration of the nursing perspective aimed to better understand care provision for children while they are in PICU.

The nursing perspective on caring for children with complex illness raised opposing views in the literature, emphasising the importance of continuity of care, establishing strong relationships and open communication with families, while concurrently voicing a reluctance for this continuity in care provision. ²² This is particularly pertinent due to the increase in children with PCCI and their frequent readmissions to hospital. Despite nurses recognising the importance of continuity of care, they voiced a reluctance to provide this care citing limited education and value of emotional support as barriers. Continuity of care also influenced the nurses' desire to leave the PICU environment; nurses desired a certain degree of this stress as it is a central aspect in their drive to become 'expert' in PICU. 42-44 The importance of clinical skills was also emphasised in the literature particularly when caring for children with chronic illness, as nurses felt this cohort of children did not require the nurses' high skill levels that were the focus of their PICU nursing. 24 42 Nurse educators suggested that mechanical ventilation, inotropic support airway support and arterial blood pressure monitoring are the most important skills for PICU nurses with no acknowledgement of non-clinical skills.⁵⁸ This further emphasised the focus on clinical skills acquisition and maintenance in PICU rather than on non-technical skills such as communication.

The concept of power in communication and care delivery was evident in PICU from the literature including within the nurse-parent relationship and nurse-Multidisciplinary team (MDT) relationship. Within the nurse-MDT relationship, as nurses gain more experience and become 'expert' in critical care they are more comfortable expressing themselves and feel increased respect from the medical team. 44 Although this level of expertise was described as a technical skill rather than an interprofessional skill.²⁴ Nurses who had more experience in high acuity care used their experience to adapt to limitations of research-supporting care such as suctioning⁴¹ and patient assessment. 33 35 Despite the technical advantage of experience, this translated to non-technical skills as they adapted communication to support families and increased their ability to contribute to discussions. This was also evident in how nurses used gatekeeping and adaptions including introducing snippets of information to families slowly to maximise understanding and acceptance. 22 51

The literature clearly showed that limited nursing access to formal discussions had significant implications for families. If the nurse did not have access to the primary information, there was an increased risk of inconsistency of information for families. Nurses felt they had an understanding of families that was not appreciated by other members of the clinical team, and in some cases were required to provide medical care that they do not agree with.⁵⁵ In other literature, nurses were described as autonomous in their clinical care, but this autonomy decreased when more complex decisions were made regarding care planning.⁵⁹ This is reflective of PICU nurses' increased involvement in ventilation weaning, feeding and sedation management. 37 60-62 In adult ICU, reduced autonomy and perceived lack of physician-nurse collaboration reduced nurse job satisfaction and thus influenced their desire to

leave critical care. ⁶³ It is reasonable to assume that this is also the case in PICU.

Limitations

Although this literature is from multiple countries, and though there are similarities in PICU care delivery, there may have been local or cultural factors that impacted the voice of the nurse due to differences in medical-nursing relationships and cultural norms. The literature search was limited to publications since 2010, almost 30% were published before 2015 which may limit its relevance in current health systems. This is particularly pertinent in an intensive care environment with constant changes in technology and following the changes in care post-COVID-19. As the primary aim of this scoping review was to map the voice of the nurse in the existing literature, the included studies were not assessed for quality. The diversity of methodologies and settings may impact transferability of these findings; however, these findings may guide further research.

CONCLUSION

This review presented how the voice of the nurse in PICU was portrayed in the literature. It identified key areas impacting the voice of the nurse in PICU including communication, competing priorities and changes in population in PICU. The expanding population of PCCI creates additional complexity for nurses as they have a conflicting desire to provide good care, to maintain skills and minimise their own distress. It also raises questions on many areas of care in the PICU with no literature depicting the voice of the nurse. Further research is needed to gain a better understanding of the voice of the nurse in the care of children in PICU at many time points.

X Kate Masterson @k8mast

Contributors All authors contributed to conceptualising and designing the study. KM and MB independently performed screening. DA reviewed any conflicting articles. KM performed initial data extraction and synthesis and MB and DA refined it. KM drafted the manuscript. MB, DA and MC made revisions. All authors read and approved the final manuscript. KM is responsible for the manuscript and acted as guarantor.

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ORCID ID

Kate Masterson http://orcid.org/0000-0001-8323-1215

REFERENCES

- 1 Polit DF, Beck CT. Nursing Research: Generating and Assessing Evidence for Nursing Practice. 11th Ed. Philadelphia: Wolters Kluwer Health. 2021.
- 2 Medeiros JA de, Almeida Júnior JJ de, Oliveira LPBA de, et al. Death and dying of newborns and children: relationships between nursing and family according to Travelbee. Rev Bras Enferm 2022;75:1–8.
- 3 Nilson C, Vieira AC, de Moura Bubadué R, et al. Decision-Making Process for the Implementation of the Child Therapeutic Support Limitation Plan: Nurses' Experiences. *Inquiry* 2022:59:469580221100777.
- 4 Cole C, Wellard S, Mummery J. Problematising autonomy and advocacy in nursing. *Nurs Ethics* 2014;21:576–82.
- 5 Sundqvist A-S, Carlsson AA. Holding the patient's life in my hands: Swedish registered nurse anaesthetists' perspective of advocacy. Scand J Caring Sci 2014;28:281–8.
- 6 Nsiah C, Siakwa M, Ninnoni JPK. Registered Nurses' description of patient advocacy in the clinical setting. Nurs Open 2019;6:1124–32.
- 7 McMillan K, Perron A. Nurses' engagement with power, voice and politics amidst restructuring efforts. *Nurs Ing* 2020;27:e12345.
- 8 Butler A, Copnell B, Willetts G. Family-centred care in the paediatric intensive care unit: an integrative review of the literature. *J Clin Nurs* 2014;23:2086–99.
- 9 Arksey H, O'Malley L. Scoping studies: towards a methodological framework. Int J Soc Res Methodol 2005;8:19–32.
- Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. *Implement Sci* 2010;5:69.
- 11 Kalu FA. What makes qualitative research good research? An exploratory analysis of critical elements. Int J Soc Sci Res 2017;5:43.
- 12 Smith GD, Gelling L, Haigh C, et al. The position of reporting guidelines in qualitative nursing research. J Clin Nurs 2018:27:889–91.
- O'Neill M, Booth S, Lamb J. Using NVivoTM for Literature Reviews: The Eight Step Pedagogy (N7+1). *TQR* 2018.
 Baird J, Davies B, Hinds PS, et al. What impact do hospital and
- 14 Baird J, Davies B, Hinds PS, et al. What impact do hospital and unit-based rules have upon patient and family-centered care in the pediatric intensive care unit? J Pediatr Nurs 2015;30:133–42.
- 15 Coats H, Bourget E, Starks H, et al. Nurses' Reflections on Benefits and Challenges of Implementing Family-Centered Care in Pediatric Intensive Care Units. Am J Crit Care 2018;27:52–8.
- 16 Felipin LCS, Merino M, Baena JA, et al. Family-centered care in neonatal and pediatric intensive care unit: nurse's vision. Cienc Cuid Saude 2018;17–2.
- 17 De Weerd W, van Tol D, Albers M, et al. Suffering in children: opinions from parents and health-care professionals. Eur J Pediatr 2015;174:589–95.
- 18 Vance AJ, Docherty S, Brandon DH. Inpatient Unit Leaders' Perspectives on Parent Engagement in Neonatal and Pediatric Intensive Care. Adv Neonatal Care 2020;00:10.
- 19 González-Gil MT, Alcolea-Cosín MT, Pérez-García S, et al. Children's visits to the paediatric intensive care unit from the nurses' experience. Enferm Intens (Eng ed) 2021;32:133–44.
- 20 Frechette J, Lavoie-Tremblay M, Kilpatrick K, et al. When the paediatric intensive care unit becomes home: A hermeneuticphenomenological study. Nurs Crit Care 2020a;25:140–8.
- 21 Park B, Oh W-O. Differences in the perceptions of partnership between nurses and mothers of children in a pediatric intensive care unit in South Korea: a qualitative study. Child Health Nurs Res 2022;28:197–207.
- 22 Butler A, Willetts G, Copnell B. Nurses' perceptions of working with families in the paediatric intensive care unit. *Nurs Crit Care* 2017;22:195–202.
- 23 Denis-Larocque G, Williams K, St-Sauveur I, et al. Nurses' perceptions of caring for parents of children with chronic medical

- complexity in the pediatric intensive care unit. *Intensive Crit Care Nurs* 2017:43:149–55.
- 24 Baird J, Rehm RS, Hinds PS, et al. Do You Know My Child? Continuity of Nursing Care in the Pediatric Intensive Care Unit. Nurs Res 2016;65:142–50.
- 25 Bloomer MJ, O'Connor M, Copnell B, et al. Nursing care for the families of the dying child/infant in paediatric and neonatal ICU: Nurses' emotional talk and sources of discomfort. A mixed methods study Aust Crit Care 2015;28:87–92.
- 26 Mesukko J, Turale S, Jintrawet U, et al. Palliative Care Guidelines for Physicians and Nurses Caring for Children and Their Families in the Pediatric Intensive Care Units: A Participatory Action Research Study. Pac Rim Int J Nurs Res 2020;24:202–18.
- 27 Mitchell S, Dale J. Advance Care Planning in palliative care: a qualitative investigation into the perspective of Paediatric Intensive Care Unit staff. *Palliat Med* 2015;29:371–9.
- 28 Henao-Castaño ÁM, Quiñonez-Mora MA. How nurses cope with death in the Paediatric Intensive Care Unit. *Enferm Intens (Eng ed)* 2019;30:163–9.
- 29 Carnevale FA, Farrell C, Cremer R, et al. Struggling to do what is right for the child: pediatric life-support decisions among physicians and nurses in France and Quebec. J Child Health Care 2012;16:109–23.
- 30 Gagnon M, Kunyk D. Beyond technology, drips, and machines: Moral distress in PICU nurses caring for end-of-life patients. *Nurs Inq* 2022;29:1–11.
- 31 Bloomer MJ, Endacott R, Copnell B, et al. Something normal in a very, very abnormal environment'--Nursing work to honour the life of dying infants and children in neonatal and paediatric intensive care in Australia. Intensive Crit Care Nurs 2016;33:5–11.
- 32 Poompan P, Fongkaew W, Mesukko J, et al. End-of-life care for children and families in pediatric intensive care: Thai nurses' perspectives. Pac Rim Int J Nurs Res 2020;24:335–48.
- 33 LaFond CM, Van Hulle Vincent C, Oosterhouse K, et al. Nurses' Beliefs Regarding Pain in Critically III Children: A Mixed-Methods Study. J Pediatr Nurs 2016;31:691–700.
- 34 LaFond CM, Van Hulle Vincent C, Corte C, et al. PICU Nurses' Pain Assessments and Intervention Choices for Virtual Human and Written Vignettes. J Pediatr Nurs 2015;30:580–90.
- 35 Mattsson JY, Forsner M, Arman M. Uncovering pain in critically ill non-verbal children: nurses' clinical experiences in the paediatric intensive care unit. J Child Health Care 2011;15:187–98.
- 36 Mattsson J, Meijers J, Björling G. Challenges in Nursing Care of Children With Substance Withdrawal Syndrome in the PICU. SAGE Open Nurs 2022;8:23779608221117382.
- 37 Craske J, Carter B, Jarman IH, et al. Nursing judgement and decision-making using the Sedation Withdrawal Score (SWS) in children. J Adv Nurs 2017;73:2327–38.
- 38 Bower RA, Coad JE, Manning JC, et al. A qualitative, exploratory study of nurses' decision-making when interrupted during medication administration within the Paediatric Intensive Care Unit. Intensive Crit Care Nurs 2018;44:11–7.
- 39 Zheng K, Sarti A, Boles S, et al. Impressions of Early Mobilization of Critically III Children-Clinician, Patient, and Family Perspectives. Pediatr Crit Care Med 2018;19:e350–7.
- 40 Deja E, Roper L, Tume LN, et al. Can they stomach it? Parent and practitioner acceptability of a trial comparing gastric residual volume measurement versus no gastric residual volume in UK NNU and PICUs: a feasibility study. Pilot Feasibility Stud 2021;7:49.
- 41 Schults JA, Cooke M, Long D, et al. "When no-one's looking," the application of lung recruitment and normal saline instillation with paediatric endotracheal suction: An exploratory study of nursing practice. Aust Crit Care 2019;32:13–9.
- 42 Frechette J, Bitzas V, Kilpatrick K, et al. A hermeneuticphenomenological study of paediatric intensive care unit nurses' professional identity following hospital redesign: Lessons learned for managers. J Nurs Manag 2020b;28:872–80.
- 43 Foglia DC, Grassley JS, Zeigler VL. Factors that influence pediatric intensive care unit nurses to leave their jobs. *Crit Care Nurs Q* 2010:33:302–16.
- 44 Mahon PR. A critical ethnographic look at paediatric intensive care nurses and the determinants of nurses' job satisfaction. *Intensive Crit* Care Nurs 2014;30:45–53.
- 45 Burton M, Caswell H, Porter C, et al. Moral Distress: Defined and Described by Neonatal and Pediatric Critical Care Nurses in a Quaternary Care Free-Standing Pediatric Hospital. Dimens Crit Care Nurs 2020;39:101–9.
- 46 Geoghegan S, Oulton K, Bull C, et al. The Challenges of Caring for Long-Stay Patients in the PICU. Pediatr Crit Care Med 2016:17:e266–71.
- 47 Stayer D, Lockhart JS. Living with Dying in the Pediatric Intensive Care Unit: A Nursing Perspective. Am J Crit Care 2016;25:350–6.

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- 48 Buckley L, Berta W, Cleverley K, et al. Exploring Pediatric Nurses' Perspectives on Their Work Environment, Work Attitudes, and Experience of Burnout: What Really Matters? Front Pediatr 2022;10:851001.
- 49 Wei H, Kifner H, Dawes ME, et al. Self-care Strategies to Combat Burnout Among Pediatric Critical Care Nurses and Physicians. Crit Care Nurse 2020;40:44–53.
- 50 Michelson KN, Patel R, Haber-Barker N, et al. End-of-life care decisions in the pediatric intensive care unit: roles professionals play. Pediatr Crit Care Med 2013;14:e34–44.
- 51 Birchley G, Gooberman-Hill R, Deans Z, et al. "Best interests" in paediatric intensive care: an empirical ethics study. Arch Dis Child 2017:102:930–5.
- 52 Watson AC, October TW. Clinical Nurse Participation at Family Conferences in the Pediatric Intensive Care Unit. Am J Crit Care 2016;25:489–97.
- 53 Walter JK, Sachs E, Schall TE, et al. Interprofessional Teamwork During Family Meetings in the Pediatric Cardiac Intensive Care Unit. J Pain Symptom Manage 2019;57:1089–98.
- 54 Dopson S, Long-Sutehall T. Exploring nurses' knowledge, attitudes and feelings towards organ and tissue donation after circulatory death within the paediatric intensive care setting in the United Kingdom: A qualitative content analysis study. *Intensive Crit Care Nurs* 2019;54:71–8.
- 55 Carnevale FA, Benedetti M, Bonaldi A, et al. Understanding the private worlds of physicians, nurses, and parents: a study of lifesustaining treatment decisions in Italian paediatric critical care. J Child Health Care 2011;15:334–49.
- 56 Kahveci R, Ayhan D, Döner P, et al. Shared decision-making in pediatric intensive care units: a qualitative study with physicians, nurses and parents. *Indian J Pediatr* 2014;81:1287–92.
- 57 Michelson KN, Emanuel L, Carter A, et al. Pediatric intensive care unit family conferences: one mode of communication for discussing end-of-life care decisions. *Pediatr Crit Care Med* 2011;12:e336–43.
- 58 Long DA, Young J, Rickard CM, et al. Analysing the role of the PICU nurse to guide education of new graduate nurses. Nurse Educ Today 2013;33:388–95.

- 59 Varjus S-L, Leino-Kilpi H, Suominen T. Professional autonomy of nurses in hospital settings--a review of the literature. Scand J Caring Sci 2011;25:201–7.
- 60 Tume LN, Kneyber MCJ, Blackwood B, et al. Mechanical Ventilation, Weaning Practices, and Decision Making in European PICUs. Pediatr Crit Care Med 2017:18:e182–8.
- 61 Tume LN, Latten L, Kenworthy L. Paediatric intensive care nurses' decision-making around gastric residual volume measurement. *Nurs Crit Care* 2017;22:293–7.
- 62 Magner C, Valkenburg AJ, Doherty D, et al. The impact of introducing nurse-led analgesia and sedation guidelines in ventilated infants following cardiac surgery. *Intensive Crit Care Nurs* 2020;60:102879.
- 63 Sawatzky J-A, Enns CL, Legare C. Identifying the key predictors for retention in critical care nurses. J Adv Nurs 2015;71:2315–25.
- 64 Page MJ, McKenzie JE, Bossuyt PM, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71.
- 65 Greenway TL, Rosenthal MS, Murtha TD, et al. Barriers to Communication in a PICU: A Qualitative Investigation of Family and Provider Perceptions. Pediatr Crit Care Med 2019;20:e415–22.
- 66 Lima L, Gonçalves S, Pinto C. Sudden death in paediatrics as a traumatic experience for critical care nurses. *Nurs Crit Care* 2018:23:42–7.
- 67 Meyer EC, Lamiani G, Foer MR, et al. What would you do if this were your child?': practitioners' responses during enacted conversations in the United States. Pediatr Crit Care Med 2012;13:e372–6.
- 68 Meyer RL. Caring for Children Who Die Unexpectedly: Patterns That Emerge Out of Chaos. J Pediatr Nurs 2014;29:23–8.
- 69 Ji J, Yang H, Yang L, et al. Nursing perspectives on transitional care between pediatric intensive care units and general wards: A focus group study. J Nurs Manag 2022.
- 70 Soares PR, Lyra da Silva CR, Quinellato Louro T. Comfort of the child in intensive pediatric therapy: perception of nursing professionals. *Rev Bras Enferm* 2020;73:1–6.
- 71 van den Bos-Boon A, Hekman S, Houmes R-J, et al. Effectiveness of Simulation Training and Assessment of PICU Nurses' Resuscitation Skills: A Mixed Methods Study from the Netherlands. J Pediatr Nurs 2021;59:e52–60.