BMJ Open

The voice of the nurse in paediatric intensive care: a scoping review

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2023-082175
Article Type:	Original research
Date Submitted by the Author:	15-Nov-2023
Complete List of Authors:	Masterson, Kate; UCD, Schoool of Nursing, Midwifery and Health Systems; Murdoch Children's Research Institute, PICU Connolly, Michael; University College Dublin, Alexander, Denise; UCD, Schoool of Nursing, Midwifery and Health Systems Brenner, Maria; University College Dublin, School of Nursing, Midwifery & Health Systems
Keywords:	Paediatric intensive & critical care < ANAESTHETICS, Nurses, Decision Making

I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our licence.

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which Creative Commons licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

Title: The voice of the nurse in paediatric intensive care: a scoping review

Abstract

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

Method Scoping review using the six-step scoping review framework outlined by Arksey and O'Malley (2005)

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

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 in 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.

Strengths and limitations of this study

- To the best of my knowledge, this is the first scoping review exploring the voice of the nurse in PICU.

-This review highlighted key areas 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.

Funding This project has received funding from the ERC under the European Union's Horizon 2020 research and innovation programme (grant agreement no. 803051).

Patient or Public Contribution No patient or public contribution as the primary author was a member of the relevant group (PICU nurses) and guided the review.

Competing interests None declared.

Introduction

The concept of voice is discussed in many contexts within healthcare literature, focusing on participant perspectives to inform and improve clinical practice, education and policy, and to identify future research needs (Polit and Beck 2021). The presence of the nursing voice in research facilitates nurses to share their experiences and perspectives on areas of importance to them (Medeiros et al. 2022; Nilson et al. 2022). Research exploring nursing engagement in 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 (McMillan and Perron 2020). The nursing voice is commonly associated with the nurses role in advocacy and autonomy (Cole et al. 2014; Sundqvist and Carlsson 2014; Nsiah et al. 2019). In paediatrics nurses are the healthcare professionals with the most contact with families, and are thus best positioned to support family presence and participation in care decisions (Butler et al. 2014a). Despite the pivotal role nurses play in care provision and communicating with families, their voices are underrepresented in the scientific literature in children's nursing, specifically within the paediatric intensive care unit (PICU).

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 (Munn et al. 2018). This review will examine how the voice of the nurse in the PICU is portrayed in the literature. This includes context and focus of the review paper and the key findings that emerge from the literature. In the context of this review, the term 'voice' pertains to the perspectives shared by nurses. A better understanding of the voice of 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.

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 (2005) and further developed by Levac et al. (2010). 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 1. 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 were 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. 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 updated in January 2023. The literature was imported into the software programme NVIVO 12 for

thematic analysis. NVIVO supports the classification and visualisation of themes facilitating the analysis of large quantities of literature (O'Neill et al. 2018).

Findings

The scoping review identified 53 articles for inclusion. The general characteristics of the articles are presented in Table 2 and the contexts of the research highlighting the area of focus are presented in Table 3. 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 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 (Baird et al. 2015; Coats et al. 2018; Felipin et al. 2018). 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 (Coats et al. 2018; Vance et al. 2020). 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 (Butler et al. 2014a; Vance et al. 2020).

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 (Vance et al. 2020). Vance et al. (2020) described the delivery of FCC as healthcare professionals giving families a plan of care which aims to manage care delivery. 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 (Coats et al. 2018; Felipin et al. 2018). 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 (Coats et al. 2018). Gonzalez-Gil et al. (2021) also noted that there was an increased parental desire to include siblings in PICU visitation, though a lack of protocol to support it.

Baird et al., (2015) 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. Nurses identified their role as rule enforcers, monitoring parental behaviour at the bedside (Frechette et al. 2020b). As a result, they became pseudo-gatekeepers, 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

(2022) 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. As a result, nurses frequently 'managed' parents through limiting information given to reduce anxiety for parents and limiting participation if they felt parental presence impeded clinical care. Similarly, Felipin et al. (2018) suggested that the process of enabling parental involvement with care is a process of facilitation and negotiation. However, this controlled parental involvement in care was not always perceived as negative, as it encouraged parents to engage with care provision when they were reluctant to do so (Butler et al. 2014b). As parents developed skills and knowledge related to their child's condition, nurses encouraged their increasing participation in care provision (Felipin et al. 2018). 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 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' (Denis-Larocque et al. 2017). Baird et al., (2016) 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 for families in providing continuity; however, they also voiced that delivering this care impacted skill maintenance and their well-being.

Death and providing care at EOL was identified as part of working in PICU, this can be sudden or expected (Mitchell and Dale 2015; Bloomer et al. 2016; Lima et al. 2018). 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 (Mesukko et al. 2020). Mitchell and Dale (2015) identified the lack of recognition of a child's illness as life-limiting as the biggest barrier for initiating the discussion of palliation. These discussions on palliation facilitate a redirection of care focused on the comfort of the child rather than interventions to prolong life (Mesukko et al. 2020). Nurses identified themselves as the health profession who recognised deterioration of children most frequently (Carnevale et al. 2012; Mitchell and Dale 2015). 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 (Gagnon and Kunyk 2022). Bloomer et al. (2016) found that the nursing role changed when care was re-directed towards palliation, nurses increased their focus on the family, and created opportunities for them to be with their child. Nurses frequently valued continuity of care in this context despite not always supporting it (Poompan et al. 2020; Medeiros et al. 2022).

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 (Mattsson et al. 2011; LaFond et al. 2015; LaFond et al. 2016). 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. (2022) explored nursing perspectives of withdrawing from sedation. They faced a 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., (2017) described nursing experience as a key factor in the assessment of withdrawal from sedation, though it was further enhanced by continuity of care.

In other areas of care delivery, Bower et al., (2018) 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. Two further studies explored views of research interventions noting nursing involvement in research planning impacted their engagement with the projects (Zheng et al. 2018; Deja et al. 2021). Schults et al., (2019) explored nursing experiences of suctioning practices in PICU. 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 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 in working in PICU and this concept influenced their intent to leave (Frechette et al. 2020a). Nurses voiced a negative personal impact of caring for children who are chronically critically ill, compared to a positive impact from caring for children they described as high acuity (Frechette et al. 2020a). This drive for obtaining clinical skills to care for high acuity children was portrayed as a central factor in a PICU nurse's identity. Foglia et al. (2010) 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. Mahon (2014) noted that this contributed to nurses' likelihood to stay in PICU as they become expert in PICU nursing. 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 (2020) 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. This included when the nurse felt the child had a poor quality of life. Gagnon and Kunyk (2022) 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. Geoghegan et al., (2016) 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. Stayer and Lockhart (2016) noted that there was increased distress for the nurses, if the child had a life-long illness leading to death, rather than death occurring after a shorter illness. Burnout was also prevalent in PICU nurses, with most nurses experiencing burnout at some point although it is difficult to self-identify (Buckley et al. 2022). Burnout 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. (2020) 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 increased resilience.

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 pre-dominantly 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 (Carnevale et al. 2012). Though, Michelson et al., (2013) suggested that the nurses primarily identify their role as that of family supporter and advocate, not as communicator. The concept of gatekeeping was evident in communication with families (Butler et al. 2014b). 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 (Birchley et al. 2017). 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 (Watson and October 2016; Walter et al. 2019). Similarly at EOL, Mesukko et al. (2020) highlighted the need for nursing presence at these family meetings during palliative and EOL care discussions to support continuity of care at the bedside. 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 (Dopson and Long-Sutehall 2019). However, competing clinical demands do not always allow the nurse to be present at the meetings.

While many studies suggested that shared decision-making occurred, there was a significant variation in the nurses' participation in this process impacted by many factors including context and patient. Carnevale et al. (2011) explored decision-making to sustain life, noting that physicians felt that nurses should not be responsible for making the decisions related to the possibility of death. Similarly, Kahveci et al. (2014) 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. Nurses acknowledged their role in the team particularly their relationship with families, however, they felt it was not their place to make decisions (Kahveci et al. 2014). Despite this nurses suggested that while they felt they did not have a responsibility in decision-making, they had a responsibility in care delivery (Carnevale et al. 2012). Nurses raised concerns that they struggle 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 (Carnevale et al. 2011). Nurses believed that their input can lead to greater consistency in decision-making, and ensures the child and families 'best-interests' are considered (Carnevale et al. 2011).

The literature also identified 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 need permission to speak (Carnevale et al. 2012; Watson and October 2016). 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 (Michelson et al. 2011; Carnevale et al. 2012).

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 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 professional practice in a context where their voice was otherwise unheard (Nilson et al. 2022). 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.

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 (Butler et al. 2014b). This is particularly pertinent due to the increase in children with PCCI and their frequent re-admissions 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 supports 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 (Foglia et al. 2010; Mahon 2014; Frechette et al. 2020a). 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 (Baird et al. 2016; Frechette et al. 2020a). 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 (Long et al. 2013). 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-MDT relationship. Within the nurse-MDT relationship, as nurses gained more experience and became 'expert' in critical care they are more comfortable expressing themselves and feel increased respect from the medical team (Mahon 2014). Although this level of expertise was described as a technical skill rather than an inter-professional skill (Baird et al. 2016). Nurses who had more experience in high acuity care used their experience to adapt to limitations of research supporting care such as suctioning (Schults et al. 2019) and patient assessment (Mattsson et al. 2011; LaFond et al. 2016). 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 (Butler et al. 2014b; Birchley et al. 2017);

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 (Carnevale et al. 2011). 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 (Varjus et al. 2011). This is reflective of PICU nurses' increased involvement in ventilation weaning, feeding and sedation management (Craske et al. 2017; Tume et al. 2017a; Tume et al. 2017b; Magner et al. 2020). 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 (Sawatzky et al. 2015). 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.

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.

References

Arksey, H. and O'Malley, L. 2005. Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology* 8(1), pp. 19–32. doi: 10.1080/1364557032000119616.

Baird, J., Davies, B., Hinds, P.S., Baggott, C. and Rehm, R.S. 2015. What Impact Do Hospital and Unit-Based Rules Have Upon Patient and Family-Centered Care in the Pediatric Intensive Care Unit? *Journal of Pediatric Nursing* 30(1), pp. 133–142. doi: 10.1016/j.pedn.2014.10.001.

Baird, J., Rehm, R.S., Hinds, P.S., Baggott, C. and Davies, B. 2016. Do You Know My Child? Continuity of Nursing Care in the Pediatric Intensive Care Unit. *Nursing Research* 65(2), pp. 142–150. doi: 10.1097/NNR.0000000000000135.

Birchley, G., Gooberman-Hill, R., Deans, Z., Fraser, J. and Huxtable, R. 2017. 'Best interests' in paediatric intensive care: an empirical ethics study. *Archives of Disease in Childhood* 102(10), pp. 930–935. doi: 10.1136/archdischild-2016-312076.

Bloomer, M.J., Endacott, R., Copnell, B. and O'Connor, M. 2016. "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 & Critical Care Nursing* 33, pp. 5–11. doi: 10.1016/j.iccn.2015.09.001.

Bower, R.A., Coad, J.E., Manning, J.C. and Pengelly, T.A. 2018. A qualitative, exploratory study of nurses' decision-making when interrupted during medication administration within the Paediatric Intensive Care Unit. *Intensive and Critical Care Nursing* 44, pp. 11–17. doi: 10.1016/j.iccn.2017.04.012.

Buckley, Berta, Cleverley, and Widger. 2022. Exploring Pediatric Nurses' Perspectives on Their Work Environment, Work Attitudes, and Experience of Burnout: What Really Matters? *Frontiers in Pediatrics* 10, p. 851001. doi: 10.3389/fped.2022.851001.

Burton, M., Caswell, H., Porter, C., Mott, S. and DeGrazia, M. 2020. Moral Distress: Defined and Described by Neonatal and Pediatric Critical Care Nurses in a Quaternary Care Free-Standing Pediatric Hospital. *Dimensions of Critical Care Nursing* 39(2), pp. 101–109. doi: 10.1097/DCC.0000000000000403.

Butler, A., Copnell, B. and Willetts, G. 2014a. Family-centred care in the paediatric intensive care unit: an integrative review of the literature. *Journal of Clinical Nursing* 23(15–16), pp. 2086–2100. doi: 10.1111/jocn.12498.

Butler, A., Copnell, and Willetts. 2014b. Nurses' perceptions on working with families in the paediatric intensive care unit (PICU). *Pediatric Critical Care Medicine* 15(4 SUPPL. 1), p. 36. doi: 10.1097/01.pcc.0000448866.09105.32.

Carnevale, Benedetti, Bonaldi, Bravi, Trabucco, and Biban. 2011. Understanding the private worlds of physicians, nurses, and parents: a study of life-sustaining treatment decisions in Italian paediatric critical care. *Journal of child health care* 15(4), pp. 334–349.

Carnevale, F.A. et al. 2012. Struggling to do what is right for the child: Pediatric life-support decisions among physicians and nurses in France and Quebec. *Journal of Child Health Care* 16(2), pp. 109–123. doi: 10.1177/1367493511420184.

Coats, H. et al. 2018. Nurses' Reflections on Benefits and Challenges of Implementing Family-Centered Care in Pediatric Intensive Care Units. *American journal of critical care* 27(1), pp. 52–58. doi: 10.4037/ajcc2018353.

Cole, C., Wellard, S. and Mummery, J. 2014. Problematising autonomy and advocacy in nursing. *Nursing Ethics* 21(5), pp. 576–582. doi: 10.1177/0969733013511362.

Craske, J., Carter, B., Jarman, I.H. and Tume, L.N. 2017. Nursing judgement and decision-making using the Sedation Withdrawal Score (SWS) in children. *Journal of advanced nursing* 73(10), pp. 2327–2338. doi: 10.1111/jan.13305.

Deja, E. et al. 2021. 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 and Feasibility Studies* 7(1), p. 49. doi: 10.1186/s40814-021-00784-5.

Denis-Larocque, G., Williams, K., St-Sauveur, I., Ruddy, M. and Rennick, J. 2017. Nurses' perceptions of caring for parents of children with chronic medical complexity in the pediatric intensive care unit. *Intensive and Critical Care Nursing* 43, pp. 149–155. doi: 10.1016/j.iccn.2017.01.010.

Dopson, S. and Long-Sutehall, T. 2019. 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 & Critical Care Nursing* 54, pp. 71–78. doi: 10.1016/j.iccn.2019.07.004.

Felipin, L.C.S., Merino, M., Baena, J.A., Oliveira, R., Borghesan, N.B.A. and Higarashi, I.H. 2018. Family-centered care in neonatal and pediatric intensive care unit: nurse's vision. *Cienc. cuid. saude*, pp. 1–7.

Foglia, D.C., Grassley, J.S. and Zeigler, V.L. 2010. Factors That Influence Pediatric Intensive Care Unit Nurses to Leave Their Jobs: *Critical Care Nursing Quarterly* 33(4), pp. 302–316. doi: 10.1097/CNQ.0b013e3181f64979.

Frechette, J., Bitzas, V., Kilpatrick, K., Aubry, M. and Lavoie-Tremblay, M. 2020a. A hermeneutic–phenomenological study of paediatric intensive care unit nurses' professional identity following hospital redesign: Lessons learned for managers. *Journal of Nursing Management (John Wiley & Sons, Inc.)* 28(4), pp. 872–880. doi: 10.1111/jonm.13012.

Frechette, J., Lavoie-Tremblay, M., Kilpatrick, K. and Bitzas, V. 2020b. When the paediatric intensive care unit becomes home: A hermeneutic-phenomenological study. *Nursing in Critical Care* 25(3), pp. 140–148. doi: 10.1111/nicc.12491.

Gagnon, M. and Kunyk, D. 2022. Beyond technology, drips, and machines: Moral distress in PICU nurses caring for end-of-life patients. *Nursing Inquiry* 29(2), pp. 1–11. doi: 10.1111/nin.12437.

Geoghegan, S., Oulton, K., Bull, C., Brierley, J., Peters, M., Jo Wray and Wray, J. 2016. The Challenges of Caring for Long-Stay Patients in the PICU. *Pediatric Critical Care Medicine* 17(6), pp. e266–e271. doi: 10.1097/PCC.0000000000000725.

Gonzalez-Gil, M.T. et al. 2021. Children's visits to the paediatric intensive care unit from the nurses' experience. *Enfermeria intensiva* 32(3), pp. 133–144. doi: 10.1016/j.enfie.2020.06.002.

Jolley, Jeremy. 2020. *Introducing Research and Evidence-Based Practice for Nursing and Healthcare Professionals.* UK: Routledge.

Kahveci, R., Ayhan, D., Doner, P., Cihan, F.G. and Koc, E.M. 2014. Shared decision-making in pediatric intensive care units: a qualitative study with physicians, nurses and parents. *Indian journal of pediatrics* 81(12), pp. 1287–92. doi: 10.1007/s12098-014-1431-6.

LaFond, C.M., Van Hulle Vincent, C., Corte, C., Hershberger, P.E., Johnson, A., Park, C.G. and Wilkie, D.J. 2015. PICU Nurses' Pain Assessments and Intervention Choices for Virtual Human and Written Vignettes. *Journal of Pediatric Nursing* 30(4), pp. 580–590. doi: 10.1016/j.pedn.2015.01.022.

LaFond, C.M., Vincent, C.V.H., Oosterhouse, K. and Wilkie, D.J. 2016. Nurses' Beliefs Regarding Pain in Critically Ill Children: A Mixed-Methods Study. *Journal of Pediatric Nursing* 31(6), pp. 691–700. doi: 10.1016/j.pedn.2016.08.002.

Levac, D., Colquhoun, H. and O'Brien, K.K. 2010. Scoping studies: advancing the methodology. *Implementation Science* 5(1), p. 69. doi: 10.1186/1748-5908-5-69.

Lima, L., Gonçalves, S. and Pinto, C. 2018. Sudden death in paediatrics as a traumatic experience for critical care nurses. *Nursing in Critical Care* 23(1), pp. 42–47. doi: 10.1111/nicc.12326.

Long, D.A., Young, J., Rickard, C.M. and Mitchell, M.L. 2013. Analysing the role of the PICU nurse to guide education of new graduate nurses. *Nurse Education Today* 33(4), pp. 388–395. doi: 10.1016/j.nedt.2013.01.016.

Magner, C., Valkenburg, A.J., Doherty, D., van Dijk, M., O'Hare, B., Segurado, R. and Cowman, S. 2020. The impact of introducing nurse-led analgesia and sedation guidelines in ventilated infants following cardiac surgery. *Intensive & critical care nursing* 60, pp. 102879–102879. doi: 10.1016/j.iccn.2020.102879.

Mahon, P.R. 2014. A critical ethnographic look at paediatric intensive care nurses and the determinants of nurses' job satisfaction. *Intensive and Critical Care Nursing* 30(1), pp. 45–53. doi: 10.1016/j.iccn.2013.08.002.

Mattsson, J., Meijers, J. and Björling, G. 2022. Challenges in Nursing Care of Children With Substance Withdrawal Syndrome in the PICU. *SAGE Open Nursing* 8, pp. 1–7. doi: 10.1177/23779608221117382.

Mattsson, J.Y., Forsner, M. and Arman, M. 2011. Uncovering pain in critically ill non-verbal children: Nurses' clinical experiences in the paediatric intensive care unit. *Journal of Child Health Care* 15(3), pp. 187–198. doi: 10.1177/1367493511406566.

McMillan, K. and Perron, A. 2020. Nurses' engagement with power, voice and politics amidst restructuring efforts. *Nursing Inquiry* 27(3), p. e12345. doi: https://doi.org/10.1111/nin.12345.

Medeiros, J.A. de, Almeida Júnior, J.J., Oliveira, L.P.B.A. de, Silva, F.R.S. da, Silva, C.C. dos S. and Barros, W.C.T. dos. 2022. Death and dying of newborns and children: relationships between nursing and family according to Travelbee. *Revista Brasileira de Enfermagem* 75(2), pp. 1–8. doi: 10.1590/0034-7167-2021-0007.

Mesukko, J., Turale, S., Jintrawet, U. and Niyomkar, S. 2020. Palliative Care Guidelines for Physicians and Nurses Caring for Children and Their Families in the Pediatric Intensive Care Units: A Participatory Action Research Study. *Pacific Rim International Journal of Nursing Research* 24(2), pp. 202–218.

Michelson, K.N., Emanuel, L., Carter, A., Brinkman, P., Clayman, M.L. and Frader, J. 2011. Pediatric intensive care unit family conferences: one mode of communication for discussing end-of-life care decisions. *Pediatric critical care medicine* 12(6), pp. e336-43. doi: 10.1097/PCC.0b013e3182192a98.

Michelson, K.N., Patel, R., Haber-Barker, N., Emanuel, L. and Frader, J. 2013. End-of-life care decisions in the pediatric intensive care unit: roles professionals play. *Pediatric critical care medicine* 14(1), pp. e34–e44. doi: 10.1097/PCC.0b013e31826e7408.

Mitchell, S. and Dale, J. 2015. Advance Care Planning in palliative care: A qualitative investigation into the perspective of Paediatric Intensive Care Unit staff. *Palliative Medicine* 29(4), pp. 371–379. doi: 10.1177/0269216315573000.

Nilson, Vieira, de Moura Bubadue, Stein, and Lago. 2022. Decision-Making Process for the Implementation of the Child Therapeutic Support Limitation Plan: Nurses' Experiences. *Inquiry : a journal of medical care organization, provision and financing* 59, p. 469580221100777. doi: 10.1177/00469580221100777.

Nsiah, C., Siakwa, M. and Ninnoni, J.P.K. 2019. Registered Nurses' description of patient advocacy in the clinical setting. *Nursing Open* 6(3), pp. 1124–1132. doi: 10.1002/nop2.307.

O'Neill, M., Booth, S. and Lamb, J. 2018. Using NVivo™ for Literature Reviews: The Eight Step Pedagogy (N7+1). *The Qualitative Report*. Available at: https://nsuworks.nova.edu/tqr/vol23/iss13/3/ [Accessed: 23 January 2023].

Park, B. and Oh, W.-O. 2022. 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 Nursing Research* 28(3), pp. 197–207. doi: 10.4094/chnr.2022.28.3.197.

Polit, D.F., author. and Beck. 2021. *Nursing research : generating and assessing evidence for nursing practice*. 11th ed. Wolters Kluwer Health.

Poompan, P., Fongkaew, W., Mesukko, J. and Niyomkar, S. 2020. End-of-life care for children and families in pediatric intensive care: Thai nurses' perspectives. *Pacific Rim International Journal of Nursing Research* 24(3), pp. 335–348.

Sawatzky, J.-A.V., Enns, C.L. and Legare, C. 2015. Identifying the key predictors for retention in critical care nurses. *Journal of advanced nursing* 71(10), pp. 2315–25. doi: 10.1111/jan.12701.

Schults, J.A., Cooke, M., Long, D. and Mitchell, M.L. 2019. "When no-one's looking," the application of lung recruitment and normal saline instillation with paediatric endotracheal suction: An exploratory study of nursing practice. *Australian Critical Care* 32(1), pp. 13–19. doi: 10.1016/j.aucc.2018.03.002.

Stayer, D. and Lockhart, J.S. 2016. Living with Dying in the Pediatric Intensive Care Unit: A Nursing Perspective. *American Journal of Critical Care* 25(4), pp. 350–356. doi: 10.4037/ajcc2016251.

Sundqvist, A.-S. and Carlsson, A.A. 2014. Holding the patient's life in my hands: Swedish registered nurse anaesthetists' perspective of advocacy. *Scandinavian Journal of Caring Sciences* 28(2), pp. 281–288. doi: https://doi.org/10.1111/scs.12057.

Tume, L.N., Kneyber, M.C.J., Blackwood, B. and Rose, L. 2017a. Mechanical Ventilation, Weaning Practices, and Decision Making in European PICUs*: *Pediatric Critical Care Medicine* 18(4), pp. e182–e188. doi: 10.1097/PCC.0000000000001100.

Tume, L.N., Latten, L. and Kenworthy, L. 2017b. Paediatric intensive care nurses' decision-making around gastric residual volume measurement. *Nursing in Critical Care* 22(5), pp. 293–297. doi: 10.1111/nicc.12304.

Vance, A.J., Docherty, S. and Brandon, D.H. 2020. Inpatient Unit Leaders' Perspectives on -Parent Engagement in Neonatal and -Pediatric Intensive Care. *Advances in Neonatal Care* 00(0), p. 10.

Varjus, S.-L., Leino-Kilpi, H. and Suominen, T. 2011. Professional autonomy of nurses in hospital settings – a review of the literature. *Scandinavian Journal of Caring Sciences* 25(1), pp. 201–207. doi: https://doi.org/10.1111/j.1471-6712.2010.00819.x.

Walter, J.K., Sachs, E., Schall, T.E., Dewitt, A.G., Miller, V.A., Arnold, R.M. and Feudtner, C. 2019. Interprofessional Teamwork During Family Meetings in the Pediatric Cardiac Intensive Care Unit. *Journal of pain and symptom management* 57(6), pp. 1089–1098. doi: 10.1016/j.jpainsymman.2019.03.002.

Watson, A.C. and October, T.W. 2016. Clinical Nurse Participation at Family Conferences in the Pediatric Intensive Care Unit. *American journal of critical care* 25(6), pp. 489–497.

Wei, H., Kifner, H., Dawes, M.E., Wei, T.L. and Boyd, J.M. 2020. Self-care strategies to combat burnout among pediatric critical care nurses and physicians. *Critical Care Nurse* 40(2), pp. 44–53. doi: 10.4037/ccn2020621.

Zheng, K. et al. 2018. Impressions of early mobilization of critically ill children—clinician, patient, and family perspectives. *Pediatric Critical Care Medicine* 19(7), pp. e350–e357. doi: 10.1097/PCC.0000000000001547.

Figure 1: PRISMA Flow Diagram

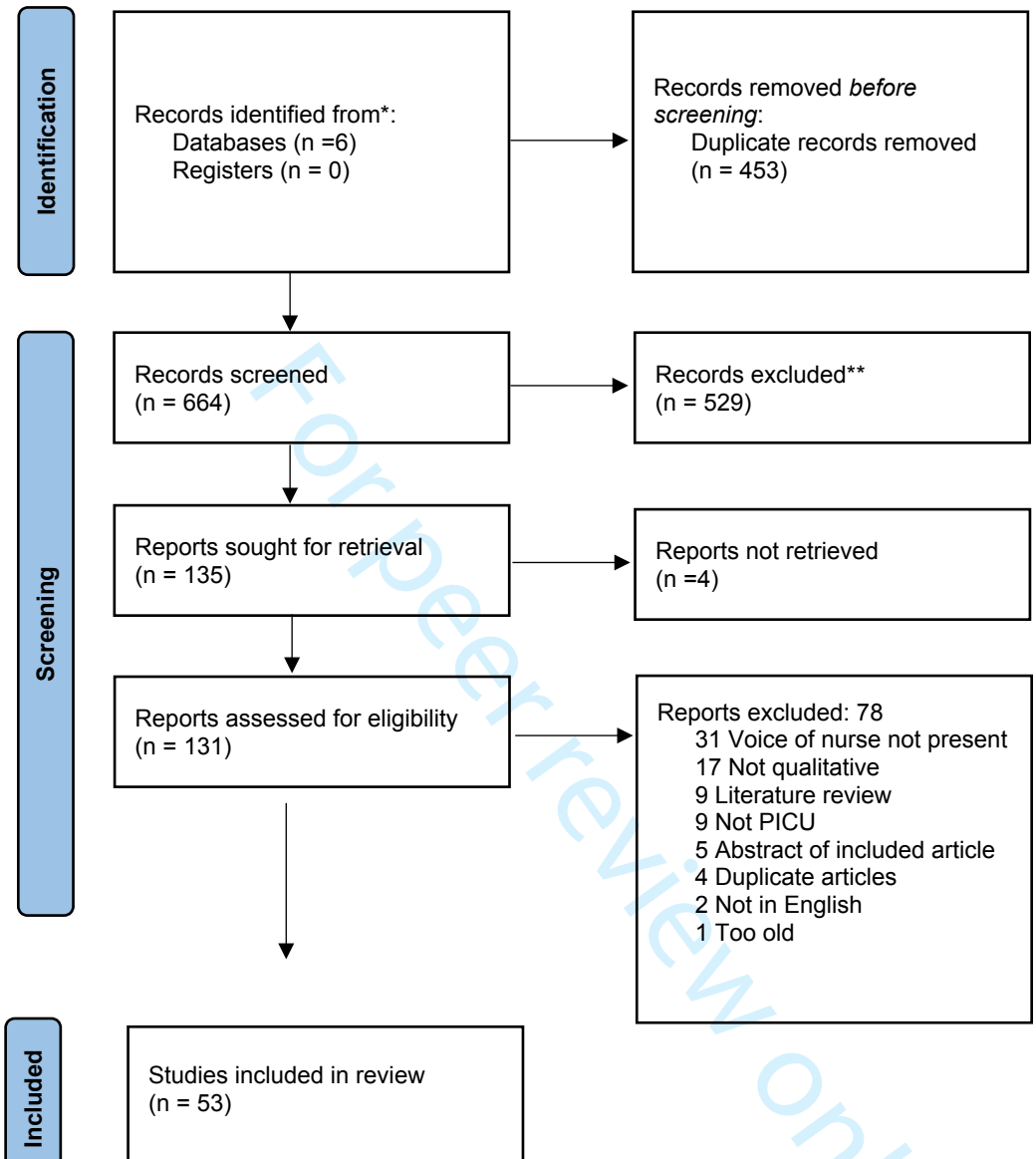

Figure 1: PRISMA Flow Diagram

From: Page. MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71. For more information, visit: http://www.prisma-statement.org/

Table 1: 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

Table 2: General characteristics of the articles included

Characteristic	Number (n=53)
Sample	
Nurses	30 (56%)
Nurses and healthcare staff	11 (20.5%)
Nurses and parents	4 (7.5%)
Nurses, healthcare staff and parents	8 (16%)
Methods	
Individual interviews	29 (54%)
Interviews and questionnaires	4 (7.5%)
Interviews and focus groups	7 (13%)
Interviews and observation	6 (11%)
Focus groups	4 (7.5%)
Focus groups and observation	2 (4%)
Observation and transcription of meetings	1 (2%)
Country	
United States	17 (32%)
Canada	7 (13%)
Europe (including UK)	15 (28%)
South America	5 (10%)
Australia	4 (7.5%)
Asia	4 (7.5%)
Multi-country	1 (2%)
Location	
Single PICU	39 (74%)
Multiple PICUs	9 (17%)
PICU/NICU	5 (9%)

Table 3: Contexts of findings

Context	Reference
Families and patients in PICU	Butler et al. 2014b; Baird et al. 2015; Baird et al. 2016; Geoghegan et al. 2016; Watson and October 2016; Denis-Larocque et al. 2017; Coats et al. 2018; Felipin et al. 2018; Greenway et al. 2019; Walter et al. 2019; Frechette et al. 2020b; Vance et al. 2020; Gonzalez-Gil et al. 2021; Park and Oh 2022
EOL in PICU	Carnevale et al. 2011; Michelson et al. 2011; Carnevale et al. 2012; Meyer et al. 2012; Michelson et al. 2013; Kahveci et al. 2014; Meyer 2014; Bloomer et al. 2015; Mitchell and Dale 2015; Bloomer et al. 2016; Stayer and Lockhart 2016; Birchley et al. 2017; Lima et al. 2018; Dopson and Long-Sutehall 2019; Henao-Castaño and Quiñonez-Mora 2019; Mesukko et al. 2020; Poompan et al. 2020; Gagnon and Kunyk 2022; Medeiros et al. 2022; Nilson et al. 2022
Healthcare delivery	Mattsson et al. 2011; De Weerd et al. 2015; LaFond et al. 2015; LaFond et al. 2016; Craske et al. 2017; Bower et al. 2018; Zheng et al. 2018; Schults et al. 2019; Rodrigues Soares et al. 2020; Deja et al. 2021; Ji et al. 2022; Mattsson et al. 2022
Nurse as a healthcare professional	Foglia et al. 2010; Mahon 2014; Burton et al. 2020; Frechette et al. 2020b; Wei et al. 2020; van den Bos-Boon et al. 2021; Buckley et al. 2022

BMJ Open

The voice of the nurse in paediatric intensive care: a scoping review

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2023-082175.R1
Article Type:	Original research
Date Submitted by the Author:	09-Jul-2024
Complete List of Authors:	Masterson, Kate; University College Dublin, School of Nursing, Midwifery and Health Systems; Murdoch Children's Research Institute, Paediatric Intensive Care Unit Connolly, Michael; University College Dublin, Schoool of Nursing, Midwifery and Health Systems Alexander, Denise; University College Dublin, Schoool of Nursing, Midwifery and Health Systems Brenner, Maria; University College Dublin, School of Nursing, Midwifery & Health Systems
Primary Subject Heading:	Nursing
Secondary Subject Heading:	Paediatrics, Intensive care, Qualitative research
Keywords:	Nurses, Decision Making, Paediatric intensive & critical care < ANAESTHETICS, Child

I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our licence.

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which Creative Commons licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

Title: The voice of the nurse in paediatric intensive care: a scoping review

Kate Masterson[1,2], Michael Connolly[1], Densie Edwards[1], Maria Brenner[1]

1. University College Dublin, School of Nursing, Midwifery and Health Systems Dublin, Ireland

2. Murdoch Children's Research Institute, Paediatric Intensive Care Unit Parkville, VIC, Australia

Corresponding author:

Full name Kate Masterson

Contact: School of Nursing, Midwifery and Health Systems, University College Dublin, Dublin 4, Ireland.

E-mail: kate.masterson@ucdconnect.ie

Keywords "Paediatric Intensive Care" "nurse" "decision-making" "communication" "scoping review"

Word count 4198

Abstract

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

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

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 programme NVIVO 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 in 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.

Strengths and limitations of this study

- To the best of my knowledge, this is the first scoping review exploring the voice of the nurse in PICU.

-This review highlighted key areas 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.

Funding This project has received funding from the ERC under the European Union's Horizon 2020 research and innovation programme (grant agreement no. 803051).

Patient or Public Contribution No patient or public contribution as the primary author was a member of the relevant group (PICU nurses) and guided the review.

Competing interests None declared.

Introduction

The concept of voice is discussed in many contexts within healthcare literature, focusing on research participant perspectives to inform and improve clinical practice, education and policy, and to identify future research needs [1]. 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 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 [7]. In paediatrics nurses are the healthcare professionals with the most contact with families, and are thus best positioned to support family presence and participation in care decisions [8]. Despite the pivotal role nurses play in care provision and communicating with families, their voices are underrepresented in the scientific literature in children's nursing, specifically within the paediatric intensive care unit (PICU).

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 (Munn et al. 2018). 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 underrepresented 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 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.

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 (2005) and further developed by Levac et al. (2010) [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 were 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 into a concept it is restricted by pre-defined variables and research tools aimed at extracting numerical data to better understand the concept [1]. 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 programme NVIVO 12 for thematic analysis. NVIVO supports the classification and visualisation of themes facilitating the analysis of large quantities of literature [13].

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 were included. Any research that described care of paediatric critical care patients were 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. 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 supplementary table.
Step 6 Consultation (optional)	They 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 H, O'Malley L. Scoping studies: towards a methodological framework. International Journal of Social Research Methodology 2005;8:19–32. https://doi.org/10.1080/1364557032000119616.*

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

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 NICUs 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.

Table 3: General characteristics of the articles included

Characteristic	Number (n=53)
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 & survey	2 (4%)
Country	
United States	16 (30%)
Canada	8 (15%)
Europe (including the UK)	15 (28%)
South America	5 (10%)
Australia	4 (7.5%)
Asia	4 (7.5%)
Multi-country	1 (2%)
Location	
Single PICU	40 (75%)
Single hospital PICU and NICU	5 (9.5%)
Multiple PICUs	3 (6%)

Table 4: Contexts of findings

Context	Reference
Families and patients in PICU	Baird *et al.*, 2015, 2016; Butler *et al.*, 2017; Coats *et al.*, 2018; Denis-Larocque *et al.*, 2017; Felipin *et al.*, 2018; Frechette *et al.*, 2020; Geoghegan *et al.*, 2016; Gonzalez-Gil *et al.*, 2021; Greenway *et al.*, 2019; Park and Oh, 2022; Vance *et al.*, 2020; Walter *et al.*, 2019; Watson and October, 2016
EOL in PICU	Birchley *et al.*, 2017; Bloomer *et al.*, 2015, 2016; Carnevale *et al.*, 2011, 2012; Dopson and Long-Sutehall, 2019; Gagnon and Kunyk, 2022; Henao-Castaño and Quiñonez-Mora, 2019; Kahveci *et al.*, 2014; Lima *et al.*, 2018; Medeiros *et al.*, 2022; Mesukko *et al.*, 2020; Meyer *et al.*, 2012; Meyer, 2014; Michelson *et al.*, 2011, Michelson and Patel *et al.*, 2013; Mitchell and Dale, 2015; Nilson *et al.*, 2022; Poompan *et al.*, 2020; Stayer and Lockhart, 2016
Healthcare delivery	Bower *et al.*, 2018; Craske *et al.*, 2017; De Weerd *et al.*, 2015; Deja *et al.*, 2021; Ji *et al.*, 2022; LaFond *et al.*, 2015, 2016; Mattsson *et al.*, 2022, 2011; Soares *et al.*, 2020; Schults *et al.*, 2019; Zheng *et al.*, 2018
Nurse as a healthcare professional	Buckley *et al.*, 2022; Burton *et al.*, 2020; Foglia *et al.*, 2010; Frechette *et al.*, 2020b; Mahon, 2014; van den Bos-Boon *et al.*, 2021; Wei *et al.*, 2020

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 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]. 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 [15,17]. 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 [8,17].

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 [17]. The delivery of FCC was described as healthcare professionals giving families a plan of care which aims to manage care delivery [17]. 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]. Gonzalez-Gil et al. (2021) also noted that there was an increased parental desire to include siblings in PICU visitation, though a lack of protocol to support it [18].

Baird et al., (2015) 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 [19]. As a result, they became pseudo-gatekeepers, 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 (2022) 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 [20]. As a result, nurses frequently 'managed' parents through limiting information given to reduce anxiety for parents and limiting participation if they felt parental presence impeded clinical care. Similarly, Felipin et al. (2018) suggested 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 with care provision when they were reluctant to do so [21]. 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 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' [22]. Baird et al., (2016) 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 for families in providing continuity; however, they also voiced that delivering this care impacted skill maintenance and their well-being [23].

Death and providing care at EOL was identified as part of working in PICU, this can be sudden or expected [24–26]. 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 [27]. Mitchell and Dale (2015) identified the lack of recognition of a child's illness as life-limiting as the biggest barrier for initiating the discussion of palliation [24]. These discussions on palliation facilitate a redirection of care focused on the comfort of the child rather than interventions to prolong life [27]. Nurses identified themselves as the health profession who recognised deterioration of children most frequently [24,28]. 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 [29]. Bloomer et al. (2016) found that the nursing role changed when care was re-directed towards palliation, nurses increased their focus on the family, and created opportunities for them to be with their child [25]. Nurses frequently valued continuity of care in this context despite not always supporting it [2,30].

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 [31–33]. 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. (2022) explored nursing perspectives of withdrawing from sedation [34]. They faced a 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., (2017) described nursing experience as a key factor in the assessment of withdrawal from sedation, though it was further enhanced by continuity of care [35].

In other areas of care delivery, Bower et al., (2018) 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 [36]. Two further studies explored views of research interventions noting nursing involvement in research planning impacted their engagement with the projects [37,38]. An Australian study explored nursing experiences of suctioning practices in PICU [39]. 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 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 in working in PICU and this concept influenced their intent to leave [40]. Nurses voiced a negative personal impact of caring for children who are chronically critically ill, compared to a positive impact from caring for children they described as high acuity [40]. This drive for obtaining clinical skills to care for high acuity children was portrayed as a central factor in a PICU nurse's identity. Foglia et al. (2010) 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 [41]. Mahon (2014) noted that this contributed to nurses' likelihood to stay in PICU as they become expert in PICU nursing [42]. 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 (2020) 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 [43]. This included when the nurse felt the child had a poor quality of life. Gagnon and Kunyk (2022) 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 [29]. Geoghegan et al., (2016) 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 [44]. Stayer and Lockhart (2016) noted that there was increased distress for the nurses, if the child had a life-long illness leading to death, rather than death occurring after a shorter illness [45]. Burnout was also prevalent in PICU nurses, with most nurses experiencing burnout at some point although it is difficult to self-identify [46]. Burnout 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. (2020) 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 increased resilience[47].

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 pre-dominantly 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 [28]. Though, Michelson et al., (2013) suggested that the nurses primarily identify their role as that of family supporter and advocate, not as communicator [48]. The concept of gatekeeping was evident in communication with families [21]. 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 [49]. 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 [50,51]. 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 [27]. 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 [52]. However, competing clinical demands do not always allow the nurse to be present at the meetings.

While many studies suggested that shared decision-making occurred, there was a significant variation in the nurses' participation in this process impacted by many factors including context and patient. Carnevale et al. (2011) explored decision-making to sustain life, noting that physicians felt that nurses should not be responsible for making the decisions related to the possibility of death [53]. Similarly, Kahveci et al. (2014) 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 [54]. Nurses acknowledged their role in the team particularly their relationship with families, however, they felt it was not their place to make decisions [54]. Despite this nurses suggested that while they felt they

did not have a responsibility in decision-making, they had a responsibility in care delivery [28]. Nurses raised concerns that they struggle 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 [53]. Nurses believed that their input can lead to greater consistency in decision-making, and ensures the child and families 'best-interests' are considered [53].

The literature also identified 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 need permission to speak [28,50]. 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 [28,55].

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 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 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 Iin 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 [21]. This is particularly pertinent due to the increase in children with PCCI and their frequent re-admissions 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 supports 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 [40–42]. 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 [23,40]. 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 [56]. 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-MDT relationship. Within the nurse-MDT relationship, as nurses gained more experience and became 'expert' in critical care they are more comfortable expressing themselves and feel increased respect from the medical team [42]. Although this level of expertise was described as a technical skill rather than an inter-professional skill [23]. Nurses who had more experience in high acuity care used their experience to adapt to limitations of research supporting care such as suctioning [39] and patient assessment [31,33]. 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 [21,49].

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 [53]. 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 [57]. This is reflective of PICU nurses' increased involvement in ventilation weaning, feeding and sedation management [35,58–60]. 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 [61]. 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.

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.

Statements

Data availability statement Data sharing not applicable – no new data generated, all articles available from source.

Ethical approval statement An ethics statement is not applicable because this study is based exclusively on published literature.

Contributorship statement 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.

References

[1] Polit DF, Beck. Nursing research : generating and assessing evidence for nursing practice. 11th ed. Philadelphia: Wolters Kluwer Health; 2021.

[2] Medeiros JA de, Almeida Júnior JJ, Oliveira LPBA de, Silva FRS da, Silva CC dos S, Barros WCT dos. Death and dying of newborns and children: relationships between nursing and family according to Travelbee. Rev Bras Enferm 2022;75:1–8. https://doi.org/10.1590/0034-7167-2021-0007.

[3] Nilson, Vieira, de Moura Bubadue, Stein, Lago. Decision-Making Process for the Implementation of the Child Therapeutic Support Limitation Plan: Nurses' Experiences. Inq J Med Care Organ Provis Financ 2022;59:469580221100777. https://doi.org/10.1177/00469580221100777.

[4] Cole C, Wellard S, Mummery J. Problematising autonomy and advocacy in nursing. Nurs Ethics 2014;21:576–82. https://doi.org/10.1177/0969733013511362.

[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. https://doi.org/10.1111/scs.12057.

[6] Nsiah C, Siakwa M, Ninnoni JPK. Registered Nurses' description of patient advocacy in the clinical setting. Nurs Open 2019;6:1124–32. https://doi.org/10.1002/nop2.307.

[7] McMillan K, Perron A. Nurses' engagement with power, voice and politics amidst restructuring efforts. Nurs Inq 2020;27:e12345. https://doi.org/10.1111/nin.12345.

[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;23:2086–100. https://doi.org/10.1111/jocn.12498.

[9] Arksey H, O'Malley L. Scoping studies: towards a methodological framework. Int J Soc Res Methodol 2005;8:19–32. https://doi.org/10.1080/1364557032000119616.

[10] Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. Implement Sci 2010;5:69. https://doi.org/10.1186/1748-5908-5-69.

[11] Kalu F, Bwalya J. What Makes Qualitative Research Good Research? An Exploratory Analysis of Critical Elements. Int J Soc Sci Res 2017;5. https://doi.org/10.5296/ijssr.v5i2.10711.

[12] Smith GD, Gelling L, Haigh C, Barnason S, Allan H, Jackson D. The position of reporting guidelines in qualitative nursing research. J Clin Nurs 2018;27:889–91. https://doi.org/10.1111/jocn.14213.

[13] O'Neill M, Booth S, Lamb J. Using NVivo™ for Literature Reviews: The Eight Step Pedagogy (N7+1). Qual Rep 2018. https://doi.org/10.46743/2160-3715/2018.3030.

[14] Baird J, Davies B, Hinds PS, Baggott C, Rehm RS. 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. https://doi.org/10.1016/j.pedn.2014.10.001.

[15] Coats H, Bourget E, Starks H, Lindhorst T, Saiki-Craighill S, Curtis JR, 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. https://doi.org/10.4037/ajcc2018353.

[16] Felipin LCS, Merino M, Baena JA, Oliveira R, Borghesan NBA, Higarashi IH. Family-centered care in neonatal and pediatric intensive care unit: nurse's vision. Cienc Cuid Saude 2018:1–7. https://doi.org/10.4025/cienccuidsaude.v17i2.41001.

[17] 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.
[18] Gonzalez-Gil MT, Alcolea-Cosin MT, Perez-Garcia S, Luna-Castano P, Torrent-Vela S, Gil-Dominguez S, et al. Children's visits to the paediatric intensive care unit from the nurses' experience. Enferm Intensiva 2021;32:133–44. https://doi.org/10.1016/j.enfie.2020.06.002.
[19] Frechette J, Lavoie-Tremblay M, Kilpatrick K, Bitzas V. When the paediatric intensive care unit becomes home: A hermeneutic-phenomenological study. Nurs Crit Care 2020a;25:140–8. https://doi.org/10.1111/nicc.12491.
[20] 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. https://doi.org/10.4094/chnr.2022.28.3.197.
[21] 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. https://doi.org/10.1111/nicc.12142.
[22] Denis-Larocque G, Williams K, St-Sauveur I, Ruddy M, Rennick J. 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. https://doi.org/10.1016/j.iccn.2017.01.010.
[23] Baird J, Rehm RS, Hinds PS, Baggott C, Davies B. Do You Know My Child? Continuity of Nursing Care in the Pediatric Intensive Care Unit. Nurs Res 2016;65:142–50. https://doi.org/10.1097/NNR.0000000000000135.
[24] 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. https://doi.org/10.1177/0269216315573000.
[25] Bloomer MJ, Endacott R, Copnell B, O'Connor M. "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. https://doi.org/10.1016/j.iccn.2015.09.001.
[26] 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. https://doi.org/10.1111/nicc.12326.
[27] Mesukko J, Turale S, Jintrawet U, Niyomkar S. 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.
[28] Carnevale FA, Farrell C, Cremer R, Canoui P, Seguret S, Gaudreault J, 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. https://doi.org/10.1177/1367493511420184.
[29] 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. https://doi.org/10.1111/nin.12437.
[30] Poompan P, Fongkaew W, Mesukko J, Niyomkar S. 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.

[31] LaFond CM, Vincent CVH, Oosterhouse K, Wilkie DJ. Nurses' Beliefs Regarding Pain in Critically Ill Children: A Mixed-Methods Study. J Pediatr Nurs 2016;31:691–700. https://doi.org/10.1016/j.pedn.2016.08.002.
[32] LaFond CM, Van Hulle Vincent C, Corte C, Hershberger PE, Johnson A, Park CG, et al. PICU Nurses' Pain Assessments and Intervention Choices for Virtual Human and Written Vignettes. J Pediatr Nurs 2015;30:580–90. https://doi.org/10.1016/j.pedn.2015.01.022.
[33] 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. https://doi.org/10.1177/1367493511406566.
[34] Mattsson J, Meijers J, Björling G. Challenges in Nursing Care of Children With Substance Withdrawal Syndrome in the PICU. SAGE Open Nurs 2022;8:1–7. https://doi.org/10.1177/23779608221117382.
[35] Craske J, Carter B, Jarman IH, Tume LN. Nursing judgement and decision-making using the Sedation Withdrawal Score (SWS) in children. J Adv Nurs 2017;73:2327–38. https://doi.org/10.1111/jan.13305.
[36] Bower RA, Coad JE, Manning JC, Pengelly TA. 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. https://doi.org/10.1016/j.iccn.2017.04.012.
[37] Zheng K, Sarti A, Boles S, Cameron S, Carlisi R, Clark H, et al. Impressions of early mobilization of critically ill children—clinician, patient, and family perspectives. Pediatr Crit Care Med 2018;19:e350–7. https://doi.org/10.1097/PCC.0000000000001547.
[38] Deja E, Roper L, Tume LN, Dorling J, Gale C, Arch B, 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. https://doi.org/10.1186/s40814-021-00784-5.
[39] Schults JA, Cooke M, Long D, Mitchell ML. "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. https://doi.org/10.1016/j.aucc.2018.03.002.
[40] Frechette J, Bitzas V, Kilpatrick K, Aubry M, Lavoie-Tremblay M. A hermeneutic–phenomenological study of paediatric intensive care unit nurses' professional identity following hospital redesign: Lessons learned for managers. J Nurs Manag 2020b;28:872–80. https://doi.org/10.1111/jonm.13012.
[41] 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. https://doi.org/10.1097/CNQ.0b013e3181f64979.
[42] 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. https://doi.org/10.1016/j.iccn.2013.08.002.
[43] Burton M, Caswell H, Porter C, Mott S, DeGrazia M. 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. https://doi.org/10.1097/DCC.0000000000000403.

[44] Geoghegan S, Oulton K, Bull C, Brierley J, Peters M, Jo Wray, et al. The Challenges of Caring for Long-Stay Patients in the PICU. Pediatr Crit Care Med 2016;17:e266–71. https://doi.org/10.1097/PCC.0000000000000725.
[45] Stayer D, Lockhart JS. Living with Dying in the Pediatric Intensive Care Unit: A Nursing Perspective. Am J Crit Care 2016;25:350–6. https://doi.org/10.4037/ajcc2016251.
[46] Buckley, Berta, Cleverley, Widger. Exploring Pediatric Nurses' Perspectives on Their Work Environment, Work Attitudes, and Experience of Burnout: What Really Matters? Front Pediatr 2022;10:851001. https://doi.org/10.3389/fped.2022.851001.
[47] Wei H, Kifner H, Dawes ME, Wei TL, Boyd JM. Self-care strategies to combat burnout among pediatric critical care nurses and physicians. Crit Care Nurse 2020;40:44–53. https://doi.org/10.4037/ccn2020621.
[48] Michelson KN, Patel R, Haber-Barker N, Emanuel L, Frader J. End-of-life care decisions in the pediatric intensive care unit: roles professionals play. Pediatr Crit Care Med 2013;14:e34–44. https://doi.org/10.1097/PCC.0b013e31826e7408.
[49] Birchley G, Gooberman-Hill R, Deans Z, Fraser J, Huxtable R. 'Best interests' in paediatric intensive care: an empirical ethics study. Arch Dis Child 2017;102:930–5. https://doi.org/10.1136/archdischild-2016-312076.
[50] Watson AC, October TW. Clinical Nurse Participation at Family Conferences in the Pediatric Intensive Care Unit. Am J Crit Care 2016;25:489–97. https://doi.org/doi:10.4037/ajcc2016817.
[51] Walter JK, Sachs E, Schall TE, Dewitt AG, Miller VA, Arnold RM, et al. Interprofessional Teamwork During Family Meetings in the Pediatric Cardiac Intensive Care Unit. J Pain Symptom Manage 2019;57:1089–98. https://doi.org/10.1016/j.jpainsymman.2019.03.002.
[52] 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. https://doi.org/10.1016/j.iccn.2019.07.004.
[53] Carnevale FA, Benedetti M, Bonaldi A, Bravi E, Trabucco G, Biban P. Understanding the private worlds of physicians, nurses, and parents: A study of life-sustaining treatment decisions in Italian paediatric critical care. J Child Health Care 2011;15:334–49. https://doi.org/10.1177/1367493511420183.
[54] Kahveci R, Ayhan D, Doner P, Cihan FG, Koc EM. Shared decision-making in pediatric intensive care units: a qualitative study with physicians, nurses and parents. Indian J Pediatr 2014;81:1287–92. https://doi.org/10.1007/s12098-014-1431-6.
[55] Michelson KN, Emanuel L, Carter A, Brinkman P, Clayman ML, Frader J. 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. https://doi.org/10.1097/PCC.0b013e3182192a98.
[56] Long DA, Young J, Rickard CM, Mitchell ML. Analysing the role of the PICU nurse to guide education of new graduate nurses. Nurse Educ Today 2013;33:388–95. https://doi.org/10.1016/j.nedt.2013.01.016.
[57] 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. https://doi.org/10.1111/j.1471-6712.2010.00819.x.

[58] Tume LN, Kneyber MCJ, Blackwood B, Rose L. Mechanical Ventilation, Weaning Practices, and Decision Making in European PICUs*: Pediatr Crit Care Med 2017;18:e182–8. https://doi.org/10.1097/PCC.0000000000001100.

[59] Tume LN, Latten L, Kenworthy L. Paediatric intensive care nurses' decision-making around gastric residual volume measurement. Nurs Crit Care 2017;22:293–7. https://doi.org/10.1111/nicc.12304.

[60] Magner C, Valkenburg AJ, Doherty D, van Dijk M, O'Hare B, Segurado R, et al. The impact of introducing nurse-led analgesia and sedation guidelines in ventilated infants following cardiac surgery. Intensive Crit Care Nurs 2020;60:102879–102879. https://doi.org/10.1016/j.iccn.2020.102879.

[61] Sawatzky J-AV, Enns CL, Legare C. Identifying the key predictors for retention in critical care nurses. J Adv Nurs 2015;71:2315–25. https://doi.org/10.1111/jan.12701.

Figure 1: PRISMA Flow Diagram

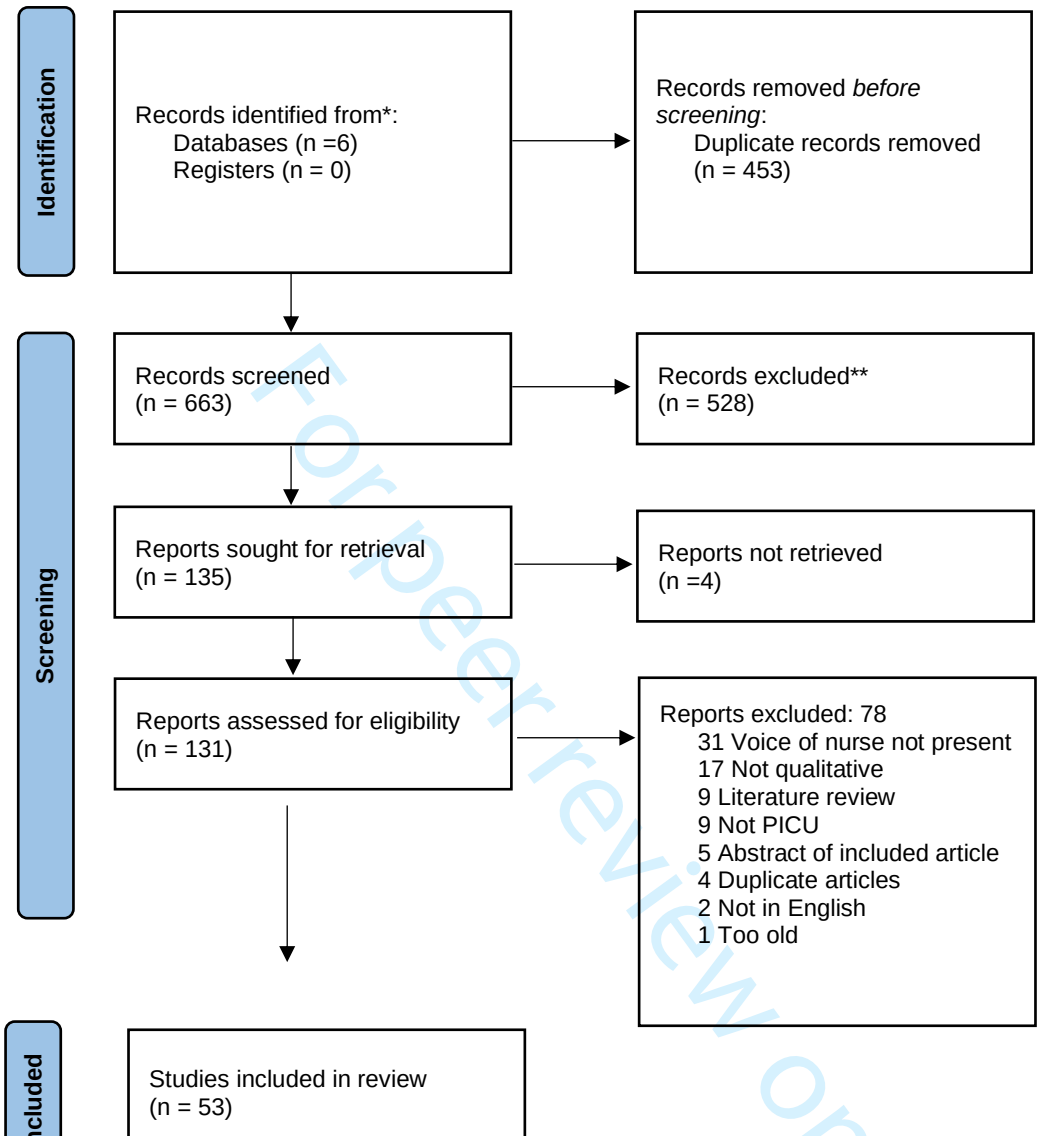

Figure 1: PRISMA Flow Diagram

From: Page. MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71. For more information, visit: http://www.prisma-statement.org/

Appendix 1 Summary of findings

Author, Year	Lead author profession	Country	Publication	Aim	Population & Setting	Methods	Context	Key findings related to voice of nurse
Baird *et al*. (2015)	Nurse	US	Journal of Pediatric Nursing	To explore the impact of hospital and unit-based rules upon patient and family-centred care in PICU	PICU Nurses (n=12) & Parents Single PICU	Interviews & observation	Families and patients in PICU	-Nurses described role as rule enforcer -Not always consistent in enforcing rules -Parents who deviate from expected behaviour labelled as 'difficult'
Baird *et al*. (2016)	Nurse	US	Nursing Research	To explore nurses' views on continuity of care	PICU Nurses (n=12) & Parents Single PICU	Interviews & observation	Families and patients in PICU	-Continuity of care valued by nurses for importance to families, allows nurses to get to know families -Can impact skill maintenance as a result nurses have desire to care for a wide variety of patients -Faces practical challenges including staffing
Birchley *et al.* (2017)	Nurse	UK	Archives of Disease in Childhood	To explore participants' experiences of decision-making in PICU related to child's 'best interests.	PICU Nurses (n=8), parents & MDT Single PICU	Interviews	EoL in PICU	-Nurses introduce snippets of information to families to help parents -Clinicians 'reframe' information to increase parental acceptance -Shared decision-making described as important but no agreement for what it means

Bloomer *et al*. (2015)	Nurse	Australia	Australian Critical Care	To explore how NICU/PICU nurses care for families before and after death	NICU and PICU nurses (n=13) Multiple PICU/NICU	Interviews & focus groups	EoL in PICU	-Nurses role to prepare families for death -They feel that they know families best and use this rapport to support families -Death part of job, -Colleagues identified as a source of support to cope with death
Bloomer *et al*. (2016)	Nurse	Australia	Intensive & Critical Care Nursing	To explore nurses' experiences of caring for children at end of life	NICU and PICU nurses (n=13) Multiple PICU/NICU	Interviews & focus groups	EoL in PICU	-Role change to focus on families as death approaches -Create opportunities to let family be with their child and create memories
Bower *et al*. (2018)	Nurse	UK	Intensive and Critical Care Nursing	To explore nurses' views on interruption during medication administration	PICU nurses (n=10) Single PICU	Interviews & observation	Healthcare delivery	-Nurses felt a need to respond to interruptions -Multi-tasking while doing meds including observing the patient -Increased focus when medication was unfamiliar
Buckley *et al*. (2022)	Nurse	Canada	Frontiers in Pediatrics	To explore paediatric nurses' perspectives on their work environment, work attitudes, and experience of burnout	NICU & PICU Nurses (n=9) PICU/NICU	Interviews	Nursing as a healthcare professional	-Burnout is complex, difficult to self-identify but regularly occurs in nurses. -Burnout also impacts ability to find meaning in work. -Variety of work, acuity of care and team help reduce burnout -Felt that their role differs to other nurses around hospital therefore need different support.
Burton *et*	Nurse	Ca	Dimension	To better understand	NICU & PICU	Focus	Nurse as	-Nurses concerned with quality

***al*. (2020)**		na da	s of Critical Care Nursing	PICU & NICU nurses understanding and experience of moral distress	Nurses (n=57) Multiple PICU/NICU	groups	a healthcare professional	of life of patients and families -Concerns that families don't have adequate information due to communication issues -Nurses input not always valued can lead to moral distress -More moral distress when nurses do not agree with care plans -Some nurses had to leave due to clinical care
Butler *et al*. (2017)	Nurse	Au str alia	Nursing in Critical Care	To explore nurses' perceptions of working with families in the PICU	PICU nurses (n=5) Single PICU	Interviews	Family and patients in PICU	-Role as gatekeeper, not necessarily negative as it supports family's involvement in care provision -Difference caring for chronic vs acute patients -Controlled delivery of information based on perceived ability of families to cope -Act as channel between medical and families for communication -Continuity of care important but variety valued more by nurses
Carnevale et al. (2011)	Nurse	Ital y	Journal of Child Health Care	To understand decision-making around life sustaining treatment in PICU in Italy	PICU Nurses (n=26), parents & MDT Single PICU	Focus groups	EoL in PICU	-Nurses felt excluded from treatment decision-making -Nurses described the important contributions that they could make, given their relationships with parents. -Decisions and care provision contribute to moral distress

Carnevale *et al*. (2012)	Nurse	France & Canada	Journal of Child Health Care	To understand decision-making around life sustaining treatment in PICU in France and Canada	PICU Nurses (n= 24) & Medical team Multiple PICUs	Focus groups	EoL in PICU	-Nurses have in-between role when communicating -Frequently absent from meetings and commonly silent even when present -Often raise life-limiting therapy before medical team
Coats *et al*. (2018)	Nurse	US	American Journal of Critical Care	To explore nurses' perspectives on providing FCC in PICU	NICU & PICU Nurses (n=10) PICU/NICU	Interviews	Family and patient in PICU	-Family presence allows relationship building and nurses give parents jobs to be involved in care -Challenging when parents distract from care provision -Can be stressful having families present -Single rooms better for families but can be isolating for nurses
Craske *et al*. (2017)	Nurse	UK	Journal of Advanced Nursing	To explore nurses' decision-making around sedation withdrawal	PICU Nurses (n=12) Single PICU	Interviews	Healthcare delivery	-Caring for children on consecutive days enhances assessment -Use parents to support assessment to help identify normal behaviour for that child -Sedation weaning score does not support complex thinking involved in decision-making related to weaning
de Weerd *et al*. (2015)	Medical	Netherlands	European Journal of Pediatrics	To explore suffering in children while in PICU	PICU nurses (n=29), parents & MDT Single PICU	Interviews	Healthcare delivery	-Nurses were focused on the signs that caused discomfort and on the treatment of this discomfort -Focused on short-term perspective on suffering

Deja *et al*. (2021)	Researcher	UK	Pilot and Feasibility Studies	To explore parent and practitioner views on the acceptability of the proposed GASTRIC trial	PICU nurses (n=31), parents & MDT Single PICU	Interviews & focus groups	Healthcare delivery	-Nurses concerned over potential change in practice even though limited evidence to support it -Focus in PICU on doing things -Different views from some junior nurses related to trial acceptability
Denis-Larocque *et al.* (2017)	Nurse	Canada	Intensive & Critical Care Nursing	To explore nurses' perceptions of caring for parents of children with chronic medical complexity in the PICU	PICU nurses (n=10) Single PICU	Interviews	Family and patient in PICU	-Challenges due to parent as expert -Need to negotiate care with parents -Takes time to establish relationships
Dopson & Long-Sutehall. (2019)	Nurse	UK	Intensive & Critical Care Nursing	To explore PICU nurses' knowledge, attitudes, and feelings when donation after circulatory death is an option at end of life	PICU Nurses (n=8) Single PICU	Interviews & focus groups	EoL in PICU	-Limited education provided on donation -Nurses may be best placed to have these conversations as they know the patients best but reluctant to do so
Felipin *et al*. (2018)	Nurse	Brazil	Ciencia, Cuidado e Saude	To explore the meaning of family Centered Care	PICU and NICU nurses (n=19) PICU/NICU	Interviews	Families and patients in PICU	-Family extension of patient, aim to involve them in patient care -Believe parents help children recover -Parents gradually learn to provide care to their child in PICU
Foglia *et al*. (2010)	Nurse	US	Critical Care Nursing Quarterly	To explore factors that influence PICU nurses to leave their jobs	PICU Nurses (n=10) Single PICU	Interviews	Nurse as a healthcare professional	-Nurses describe the challenges of caring for sick children as a positive -Insufficient resources and support are stressors -Unrelieved stress as major reason leave job

Frechette *et al*. (2020a)	Nurse	Canada	Nursing in Critical Care	To examine PICU nurses' lived experience of caring for families following a major hospital transformation project.	PICU Nurses (n=15) Single PICU	Interviews & observation	Families and patients in PICU	-Gatekeeping occurs when nurse enforce rules and dictate parental role in care -Value an environment that offers personalised care -Often focused on the child rather than the family
Frechette *et al*. (2020b)	Nurse	Canada	Journal of Nursing Management	To explore nurses' professional identity following a redesign	PICU Nurses (n=15) Single PICU	Interviews & observation	Nurse a healthcare professional	-Reluctance to care for chronic long-term patients due to moral distress and pull from acute patients -Can be challenging to adjust to different care needs for chronic patients eg. Less monitoring -Can result in increased patient load when less acute which is challenging in single rooms
Gagnon & Kunyk (2022)	Nurse	Canada	Nursing Inquiry	To explore the moral distress experiences of PICU nurses caring for child patients who are dying	PICU Nurses (n=7) Multiple PICUs	Interviews	EoL in PICU	-Desire to give children dignified death that was peaceful -Burden of knowledge as an insider but not able to share with families can cause moral distress -Limited ability to be heard in decision-making -Use of language to communicate nurses' perspective -Nurse can experience moral distress when dignity not prioritised
Geoghegan	Resear	UK	Pediatric	To explore the	NICU & PICU	Interview	Families	-Significant impact of caring for

***et al*. (2016)**	cher		Critical Care Medicine	challenges of caring for long-stay patients in the PICU	Nurses (n=7) & MDT Single PICU	s	and patients in PICU	long-stay patients (LSP)- moral distress and low morale -Desire for variety of patients, particularly acute patients -Patients with no long-term plan most challenging
Gonzalez-Gil *et al*. (2021)	Nurse	Spain	Enfermeria Intensiva	To explore nurses' experience related to promoting the visits of siblings to PICU	PICU nurses (n=12) Single PICU	Interviews	Families and patients in PICU	-Emerging demand for sibling visits but no policy -Decisions not documented making consistency difficult -Overall nurses support visits but need to prepare environment to minimise distress
Greenway *et al*. (2019)	Medical	US	Pediatric critical care medicine	To explore barriers to communication in PICU	PICU nurses (n=3), parents & MDT Single PICU	Interviews	Families and patients in PICU	-Breakdown in communication when deviation from plan -Difference in findings from families, limited presentation of voice of nurse.
Henao-Castano & Quinonez-Mora (2019)	Nurse	Colombia	Enferm Intensiva	To explore nurses' coping with death in PICU	PICU nurses (n=10) Single PICU	Interviews	EoL in PICU	-Value of good communication -Focus on care provision at end of life and meaning from work
Ji *et al*. (2022)	Nurse	China	Journal of Nursing Management.	To explore ward and PICU nurses experiences of transferring patients out of PICU	Ward and PICU nurses (n= 14) Single PICU	Focus groups	Healthcare delivery	-Different priorities between ward and PICU nurses -Request for written handover to improve communication
Kahveci *et al*. (2014)	Medical	Turkey	Indian journal of pediatrics	To understand how decisions are made in PICU settings where critically ill children require life-support	PICU nurses (n=9), parents & MDT	Interviews	EoL in PICU	- Should be physician's responsibility to make the decisions in medically critical situations. - Nurses seemed to have more

				decision	Single PICU			understanding of the parents' feelings, compared to the doctors. -Decision-making gets easier with more experience in PICU
LaFond *et al*. (2015)	Nurse	US	Journal of Pediatric Nursing	To explore factors nurses, consider when assessing pain and selecting interventions in PICU	PICU nurses (n=40) Single PICU	Interviews & vignette questionnaires	Healthcare deliv	-PICU nurses used their own assessment over patient reported pain scores
LaFond *et al*. (2016)	Nurse	US	Journal of Pediatric Nursing	To describe PICU nurses' beliefs regarding the assessment and management of children's pain.	PICU nurses (n=40) Single PICU	Interviews & vignette questionnaire	Healthcare deliv	-Nurses use behaviour to describe pain over pain scores -Each patient unique making self-report difficult to rely on -Use experience to guide assessment
Lima *et al*. (2018)	Psychologist	Portugal	Nursing in critical care	To describe PICU nurses experiences with the sudden death of children/adolescents	NICU & PICU (n=36) Nurses Multiple PICU/NICU	Interviews & questionnaire	EoL in PICU	-Sudden death of patients resulted in significant impact on nurses -Experience helped with coping -Limited training and local support for this situation
Mahon (2014)	Nurse	Canada	Intensive and Critical Care Nursing	To explore PICU nurses job satisfaction through an ethnographic view of PICU	PICU Nurses (n=31) Single PICU	Interviews & observation	Nursing as a healthcare professional	-Change in way nurses spoke and communicate with experience -Value on experience and education -Lack of respect and power imbalance contributes to staff leaving -Value in provision of 'good death' doesn't contribute to intent to leave
Mattsson *et al*. (2011)	Nurse	Swed	Journal of Child	To explore nurses' clinical experiences of	PICU Nurses (n=17)	Interviews	Healthcare deliver	-Assessment on patient presentation

		en	Health Care	pain in non-verbal children in the PICU	Single PICU			-Use of experience to measure pain -Need to know patient baseline
Mattsson *et al*. (2022)	Nurse	Sweeden	SAGE Open Nursing	To explore nurses' challenges caring for children with substance withdrawal in the PICU	PICU nurses (n=5) Single PICU	Interviews	Healthcare delivery	-Focus on weaning to child's need not to desire to discharge from PICU -Need for correct language to communicate assessment based on experience
Medeiros *et al*. (2022)	Nurse	Brazil	Revista Brasileira de Enfermagem	To explore staff perceptions of their relationship with families of children during palliative care in PICU	NICU & PICU nurses and nurse technicians* (n=17) PICU/NICU	Interviews	EoL PICU	-Staff impacted by family acceptance of death -Influenced by communication of medical prognosis and false hope -Focus on care needs of child including keeping them pain free and family needs
Mesukko *et al*. (2020)	Nurse	Thailand	Pacific Rim International Journal of Nursing Research	To explore perspective of palliative care in PICU	PICU nurses (n=41) & medical team Multiple PICU/NICU	Interviews & focus groups	EoL PICU	-Communication essential for good pal care -Nurses should be at all planning meetings -Need for continuity of care at EoL -Nurses led symptom management related to EoL
Meyer (2014)	Nurse	US	Journal of Pediatric Nursing	To explore nurses' experiences caring for dying children	PICU Nurses (n=10) Single PICU	Interviews	EoL in PICU	-Difference in caring for children who are expected to die versus those who die unexpectedly in the same shift -When nurses realise approach of death, anxiety occurs until family updated -Step back emotionally from situation -Nurses provide care physically

								and medically and focus on creating order in the chaos
Meyer *et al*. (2012)	Nurse	US	Pediatric Critical Care Medicine	To explore practitioners' response to parents asking, 'what would you do if this is your child?' during simulation in PICU	PICU nurses (n=13) & MDT Single PICU	Simulation & interviews	EoL in PICU	-Focus on providing clinical information -Varied responses from practitioners including sharing personal information -Nurses focus on offering support
Michelson *et al*. (2011)	Medical	US	Pediatric Critical Care Medicine	To explore the processes used in EoL decision-making and the roles in family conferences (FC)	PICU nurses (n=23), parents & MDT Single PICU	Interviews & focus groups	EoL in PICU	-FC used to coordinate care and for communication -Nurses act as advocates -Nurses often asked questions after meeting even when not there -Nurses often absent due to competing demands
Michelson and Patel *et al*. (2013)	Medical	US	Pediatric Critical Care Medicine	To explore roles at end-of-life care	PICU nurses (n=23), parents & MDT Single PICU	Interviews & focus groups	EoL in PICU	-Nurses often act as family supporter and advocate -Information mainly given by medical team -Nurses often play role of secondary decision maker by censoring information given to families
Mitchell & Dale (2015)	Medical	UK	Palliative Medicine	To explore views regarding advance care planning (ACP) in pal care in PICU	PICU nurses (n=6) & medical team Single PICU	Interviews	EoL in PICU	-Failure to recognise approach of death stops ACP in practice -Nurses often recognise approach of EoL first -Considered good idea but needs MDT involvement -Moral distress when not acting in best interest of patient
Nilson *et al*. (2022)	Nurse	Brazil	Inquiry	To explore nurses' experience of the	PICU Nurses (n=25)	Interviews	EoL in PICU	-Research allowed nurses an opportunity to discuss this

				decision-making process related to therapeutic support limitation in PICU	Multiple PICUs			issue where they normally don't have voice -Predominantly mediator in decision-making -Feelings of frustration from exclusion
Park & Oh (2022)	Nurse	Korea	Child Health Nursing Research	To explore nurses and mothers' perceptions of partnership in PICU	PICU nurses (n=12) & Parents Single PICU	Interviews	Family and patient in PICU	-Differing views on partnership, nurses believe unequal due to knowledge imbalance -Focus on clinical care, reluctance to deliver information
Poompan *et al*. (2020)	Nurse	Thailand	Pacific Rim International Journal of Nursing Research	To explore experiences of EoL care in a Thai PICU	PICU nurses (n=24) & Parents Single PICU	Interviews & observation	EoL in PICU	-Nurses had to wait for medical team to redirect care before providing EoL care -Once change to comfort nurses lead care and support parents to make decisions and provide care -Nurses coordinate communication
Soares *et al*. (2020)	Nurse	Brazil	Revista Brasileira de Enfermagem	To explore nurses' perceptions of comfort in PICU	PICU nurses (n=40) and nurse technicians* Single PICU	Interviews	Healthcare delivery	-Nurses aim to promote comfort -Includes environmental for example noise and care specific including pain interventions
Schults *et al*. (2019)	Nurse	Australia	Australian Critical Care	To explore nursing practice of suctioning in PICU	PICU nurses (n=12) Single PICU	Interviews	Healthcare delivery	-Nurses use experience to decide suctioning practice -Aware of lack of research- they rely on own practice
Stayer & Lockhart (2020)	Nurse	US	American Journal of Critical	To explore PICU nurses' ability to cope with death	PICU nurses (n=12)	Interviews	EoL in PICU	-Death part of the job but its emotionally demanding -Focus on providing peaceful

			Care		Single PICU			end of children -Very hard when hope taken away but harder when reluctance to talk about death by medical team
van den Bos-Boon *et al*. (2021)	Nurse	Netherlands	Journal of Pediatric Nursing	To explore the effectiveness of sim training in resus skills	PICU nurses (n=19) Single PICU	Interviews & simulation observation	Nurse as a healthcare professional	-Sim training increased nurses' confidence in resus skills -Nurses had limited recognition of improvement of leadership communication during sim (traditionally medical led)
Vance *et al*. (2020)	Nurse	US	Advances in Neonatal Care	To explore perspectives in facilitating FCC	NICU & PICU Nurses (n=10) & Medical PICU/NICU	Interviews	Family and patients in PICU	-FCC nurse dependent -To promote FCC, they focused on communication to get everyone on same page -Decision-making happens ongoing not at a point in time -Unit design impacts FCC
Walter *et al*. (2019)	Medical	US	Journal of Pain and Symptom Management	To assess teamwork and communication with parents during family meetings.	PICU nurses (n=11) & medical Single PICU	Observation & Survey	Families and patients in PICU	-Nurses' contribution focused on providing medical information related to care at the bedside -They offered support and clarified elements for families
Watson & October (2016)	Nurse	US	American Journal of Critical Care	To explore clinical nurse participation in family meetings	PICU nurses (47 survey & nurses in meetings) Single PICU	Observation & survey	Families and patients in PICU	-A clinical nurse attended 20 (50%) of the family conferences that were audio-recorded but only made contribution in 25% of them. -Unable to attend due to clinical demands -Being present allows them to be present to hear news firsthand -nurses who did not speak said

								they had wanted to speak, and some of the reasons provided were that they were "uncomfortable speaking," "were not asked"
Wei *et al*. (2020)	Nurse	US	Critical Care Nurse	To explore self-care to prevent burnout for staff in PICU	PICU nurses (n=13) & Medical Single PICU	Interviews	Nurse as a healthcare professional	-Finding meaning in work kept staff motivated -Support from colleagues important
Zheng *et al*. (2018)	Researcher	Canada	Pediatric Critical Care Medicine	To explore impressions of early mobilization of critically ill children	PICU nurses (n=10), parents & MDT Single PICU	Interviews	Healthcare delivery	-Early mobility important but not a priority -Felt like they had responsibility, but it increased workload

BMJ Open

The voice of the nurse in paediatric intensive care: a scoping review

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2023-082175.R2
Article Type:	Original research
Date Submitted by the Author:	30-Sep-2024
Complete List of Authors:	Masterson, Kate; University College Dublin, School of Nursing, Midwifery and Health Systems; Murdoch Children's Research Institute, Paediatric Intensive Care Unit Connolly, Michael; University College Dublin, Schoool of Nursing, Midwifery and Health Systems Alexander, Denise; University College Dublin, Schoool of Nursing, Midwifery and Health Systems Brenner, Maria; University College Dublin, School of Nursing, Midwifery & Health Systems
Primary Subject Heading:	Nursing
Secondary Subject Heading:	Paediatrics, Intensive care, Qualitative research
Keywords:	Nurses, Decision Making, Paediatric intensive & critical care < ANAESTHETICS, Child

I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our licence.

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which Creative Commons licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

Title: The voice of the nurse in paediatric intensive care: a scoping review

Kate Masterson[1,2], Michael Connolly[1], Densie Alexander[1], Maria Brenner[1]

1. University College Dublin, School of Nursing, Midwifery and Health Systems
Dublin, Ireland

2. Murdoch Children's Research Institute, Paediatric Intensive Care Unit
Parkville, VIC, Australia

Corresponding author:

Full name Kate Masterson

Contact: School of Nursing, Midwifery and Health Systems, University College Dublin,

Dublin 4, Ireland.

E-mail: kate.masterson@ucdconnect.ie

Keywords “Paediatric Intensive Care” “nurse” “decision-making” “communication” “scoping review”

Word count 4198

Abstract

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

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

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 programme NVIVO 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 in 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.

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 PICU.

-This review highlighted key areas 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.

Funding This project has received funding from the ERC under the European Union's Horizon 2020 research and innovation programme (grant agreement no. 803051).

Patient or Public Contribution No patient or public contribution as the primary author was a member of the relevant group (PICU nurses) and guided the review.

Competing interests None declared.

Introduction

The concept of voice is discussed in many contexts within healthcare literature, focusing on research participant perspectives to inform and improve clinical practice, education and policy, and to identify future research needs [1]. 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 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 [7]. In paediatrics nurses are the healthcare professionals with the most contact with families, and are thus best positioned to support family presence and participation in care decisions [8]. Despite the pivotal role nurses play in care provision and communicating with families, their voices are underrepresented in the scientific literature in 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 (Munn et al. 2018). 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 underrepresented 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 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.

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 (2005) and further developed by Levac et al. (2010) [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 were 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 into a concept it is restricted by pre-defined variables and research tools aimed at extracting numerical data to better understand the concept [1].

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 programme NVIVO 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 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 were included. Any research that described care of paediatric critical care patients were 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. 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 supplementary table.
Step 6 Consultation (optional)	They 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 H, O'Malley L. Scoping studies: towards a methodological framework. International Journal of Social Research Methodology 2005;8:19–32. https://doi.org/10.1080/1364557032000119616.*

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

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 NICUs 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.

Table 3: General characteristics of the articles included

Characteristic	Number (n=53)
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 & survey	2 (4%)
Country	
United States	16 (30%)
Canada	8 (15%)
Europe (including the UK)	15 (28%)
South America	5 (10%)
Australia	4 (7.5%)
Asia	4 (7.5%)
Multi-country	1 (2%)
Location	
Single PICU	40 (75%)
Single hospital PICU and NICU	5 (9.5%)
Multiple PICUs	3 (6%)

Table 4: Contexts of findings

Context	Reference
Families and patients in PICU	Baird *et al.*, 2015, 2016; Butler *et al.*, 2017; Coats *et al.*, 2018; Denis-Larocque *et al.*, 2017; Felipin *et al.*, 2018; Frechette *et al.*, 2020; Geoghegan *et al.*, 2016; Gonzalez-Gil *et al.*, 2021; Greenway *et al.*, 2019; Park and Oh, 2022; Vance *et al.*, 2020; Walter *et al.*, 2019; Watson and October, 2016
EOL in PICU	Birchley *et al.*, 2017; Bloomer *et al.*, 2015, 2016; Carnevale *et al.*, 2011, 2012; Dopson and Long-Sutehall, 2019; Gagnon and Kunyk, 2022; Henao-Castaño and Quiñonez-Mora, 2019; Kahveci *et al.*, 2014; Lima *et al.*, 2018; Medeiros *et al.*, 2022; Mesukko *et al.*, 2020; Meyer *et al.*, 2012; Meyer, 2014; Michelson *et al.*, 2011, Michelson and Patel *et al.*, 2013; Mitchell and Dale, 2015; Nilson *et al.*, 2022; Poompan *et al.*, 2020; Stayer and Lockhart, 2016
Healthcare delivery	Bower *et al.*, 2018; Craske *et al.*, 2017; De Weerd *et al.*, 2015; Deja *et al.*, 2021; Ji *et al.*, 2022; LaFond *et al.*, 2015, 2016; Mattsson *et al.*, 2022, 2011; Soares *et al.*, 2020; Schults *et al.*, 2019; Zheng *et al.*, 2018
Nurse as a healthcare professional	Buckley *et al.*, 2022; Burton *et al.*, 2020; Foglia *et al.*, 2010; Frechette *et al.*, 2020b; Mahon, 2014; van den Bos-Boon *et al.*, 2021; Wei *et al.*, 2020

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 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]. 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 [15,17]. 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 [8,17].

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 [17]. The delivery of FCC was described as healthcare professionals giving families a plan of care which aims to manage care delivery [17]. 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]. Gonzalez-Gil et al. (2021) also noted that there was an increased parental desire to include siblings in PICU visitation, though a lack of protocol to support it [18].

Baird et al., (2015) 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 [19]. As a result, they became pseudo-gatekeepers, 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 (2022) 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 [20]. As a result, nurses frequently 'managed' parents through limiting information given to reduce anxiety for parents and limiting participation if they felt parental presence impeded clinical care. Similarly, Felipin et al. (2018) suggested 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 with care provision when they were reluctant to do so [21]. 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 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' [22]. Baird et al., (2016) 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 for families in providing continuity; however, they also voiced that delivering this care impacted skill maintenance and their well-being [23].

Death and providing care at EOL was identified as part of working in PICU, this can be sudden or expected [24–26]. 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 [27]. Mitchell and Dale (2015) identified the lack of recognition of a child's illness as life-limiting as the biggest barrier for initiating the discussion of palliation [24]. These discussions on palliation facilitate a redirection of care focused on the comfort of the child rather than interventions to prolong life [27]. Nurses identified themselves as the health profession who recognised deterioration of children most frequently [24,28]. 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 [29]. Bloomer et al. (2016) found that the nursing role changed when care was re-directed towards palliation, nurses increased their focus on the family, and created opportunities for them to be with their child [25]. Nurses frequently valued continuity of care in this context despite not always supporting it [2,30].

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 [31–33]. 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. (2022) explored nursing perspectives of withdrawing from sedation [34]. They faced a 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., (2017) described nursing experience as a key factor in the assessment of withdrawal from sedation, though it was further enhanced by continuity of care [35].

In other areas of care delivery, Bower et al., (2018) 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 [36]. Two further studies explored views of research interventions noting nursing involvement in research planning impacted their engagement with the projects [37,38]. An Australian study explored nursing experiences of suctioning practices in PICU [39]. 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 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 in working in PICU and this concept influenced their intent to leave [40]. Nurses voiced a negative personal impact of caring for children who are chronically critically ill, compared to a positive impact from caring for children they described as high acuity [40]. This drive for obtaining clinical skills to care for high acuity children was portrayed as a central factor in a PICU nurse's identity. Foglia et al. (2010) 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 [41]. Mahon (2014) noted that this contributed to nurses' likelihood to stay in PICU as they become expert in PICU nursing [42]. 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 (2020) 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 [43]. This included when the nurse felt the child had a poor quality of life. Gagnon and Kunyk (2022) 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 [29]. Geoghegan et al., (2016) 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 [44]. Stayer and Lockhart (2016) noted that there was increased distress for the nurses, if the child had a life-long illness leading to death, rather than death occurring after a shorter illness [45]. Burnout was also prevalent in PICU nurses, with most nurses experiencing burnout at some point although it is difficult to self-identify [46]. Burnout 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. (2020) 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 increased resilience[47].

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 pre-dominantly 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 [28]. Though, Michelson et al., (2013) suggested that the nurses primarily identify their role as that of family supporter and advocate, not as communicator [48]. The concept of gatekeeping was evident in communication with families [21]. 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 [49]. 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 [50,51]. 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 [27]. 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 [52]. However, competing clinical demands do not always allow the nurse to be present at the meetings.

While many studies suggested that shared decision-making occurred, there was a significant variation in the nurses' participation in this process impacted by many factors including context and patient. Carnevale et al. (2011) explored decision-making to sustain life, noting that physicians felt that nurses should not be responsible for making the decisions related to the possibility of death [53]. Similarly, Kahveci et al. (2014) 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 [54]. Nurses acknowledged their role in the team particularly their relationship with families, however, they felt it was not their place to make decisions [54]. Despite this nurses suggested that while they felt they

did not have a responsibility in decision-making, they had a responsibility in care delivery [28]. Nurses raised concerns that they struggle 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 [53]. Nurses believed that their input can lead to greater consistency in decision-making, and ensures the child and families 'best-interests' are considered [53].

The literature also identified 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 need permission to speak [28,50]. 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 [28,55].

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 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 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 Iin 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 [21]. This is particularly pertinent due to the increase in children with PCCI and their frequent re-admissions 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 supports 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 [40–42]. 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 [23,40]. 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 [56]. 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-MDT relationship. Within the nurse-MDT relationship, as nurses gained more experience and became 'expert' in critical care they are more comfortable expressing themselves and feel increased respect from the medical team [42]. Although this level of expertise was described as a technical skill rather than an inter-professional skill [23]. Nurses who had more experience in high acuity care used their experience to adapt to limitations of research supporting care such as suctioning [39] and patient assessment [31,33]. 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 [21,49].

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 [53]. 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 [57]. This is reflective of PICU nurses' increased involvement in ventilation weaning, feeding and sedation management [35,58–60]. 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 [61]. 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.

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.

Statements

Data availability statement Data sharing not applicable – no new data generated, all articles available from source.

Ethical approval statement An ethics statement is not applicable because this study is based exclusively on published literature.

Contributorship statement 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.

References

[1] Polit DF, Beck. Nursing research : generating and assessing evidence for nursing practice. 11th ed. Philadelphia: Wolters Kluwer Health; 2021.

[2] Medeiros JA de, Almeida Júnior JJ, Oliveira LPBA de, Silva FRS da, Silva CC dos S, Barros WCT dos. Death and dying of newborns and children: relationships between nursing and family according to Travelbee. Rev Bras Enferm 2022;75:1–8. https://doi.org/10.1590/0034-7167-2021-0007.

[3] Nilson, Vieira, de Moura Bubadue, Stein, Lago. Decision-Making Process for the Implementation of the Child Therapeutic Support Limitation Plan: Nurses' Experiences. Inq J Med Care Organ Provis Financ 2022;59:469580221100777. https://doi.org/10.1177/00469580221100777.

[4] Cole C, Wellard S, Mummery J. Problematising autonomy and advocacy in nursing. Nurs Ethics 2014;21:576–82. https://doi.org/10.1177/0969733013511362.

[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. https://doi.org/10.1111/scs.12057.

[6] Nsiah C, Siakwa M, Ninnoni JPK. Registered Nurses' description of patient advocacy in the clinical setting. Nurs Open 2019;6:1124–32. https://doi.org/10.1002/nop2.307.

[7] McMillan K, Perron A. Nurses' engagement with power, voice and politics amidst restructuring efforts. Nurs Inq 2020;27:e12345. https://doi.org/10.1111/nin.12345.

[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;23:2086–100. https://doi.org/10.1111/jocn.12498.

[9] Arksey H, O'Malley L. Scoping studies: towards a methodological framework. Int J Soc Res Methodol 2005;8:19–32. https://doi.org/10.1080/1364557032000119616.

[10] Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. Implement Sci 2010;5:69. https://doi.org/10.1186/1748-5908-5-69.

[11] Kalu F, Bwalya J. What Makes Qualitative Research Good Research? An Exploratory Analysis of Critical Elements. Int J Soc Sci Res 2017;5. https://doi.org/10.5296/ijssr.v5i2.10711.

[12] Smith GD, Gelling L, Haigh C, Barnason S, Allan H, Jackson D. The position of reporting guidelines in qualitative nursing research. J Clin Nurs 2018;27:889–91. https://doi.org/10.1111/jocn.14213.

[13] O'Neill M, Booth S, Lamb J. Using NVivo™ for Literature Reviews: The Eight Step Pedagogy (N7+1). Qual Rep 2018. https://doi.org/10.46743/2160-3715/2018.3030.

[14] Baird J, Davies B, Hinds PS, Baggott C, Rehm RS. 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. https://doi.org/10.1016/j.pedn.2014.10.001.

[15] Coats H, Bourget E, Starks H, Lindhorst T, Saiki-Craighill S, Curtis JR, 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. https://doi.org/10.4037/ajcc2018353.

[16] Felipin LCS, Merino M, Baena JA, Oliveira R, Borghesan NBA, Higarashi IH. Family-centered care in neonatal and pediatric intensive care unit: nurse's vision. Cienc Cuid Saude 2018:1–7. https://doi.org/10.4025/cienccuidsaude.v17i2.41001.

[17] 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.
[18] Gonzalez-Gil MT, Alcolea-Cosin MT, Perez-Garcia S, Luna-Castano P, Torrent-Vela S, Gil-Dominguez S, et al. Children's visits to the paediatric intensive care unit from the nurses' experience. Enferm Intensiva 2021;32:133–44. https://doi.org/10.1016/j.enfie.2020.06.002.
[19] Frechette J, Lavoie-Tremblay M, Kilpatrick K, Bitzas V. When the paediatric intensive care unit becomes home: A hermeneutic-phenomenological study. Nurs Crit Care 2020a;25:140–8. https://doi.org/10.1111/nicc.12491.
[20] 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. https://doi.org/10.4094/chnr.2022.28.3.197.
[21] 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. https://doi.org/10.1111/nicc.12142.
[22] Denis-Larocque G, Williams K, St-Sauveur I, Ruddy M, Rennick J. 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. https://doi.org/10.1016/j.iccn.2017.01.010.
[23] Baird J, Rehm RS, Hinds PS, Baggott C, Davies B. Do You Know My Child? Continuity of Nursing Care in the Pediatric Intensive Care Unit. Nurs Res 2016;65:142–50. https://doi.org/10.1097/NNR.0000000000000135.
[24] 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. https://doi.org/10.1177/0269216315573000.
[25] Bloomer MJ, Endacott R, Copnell B, O'Connor M. "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. https://doi.org/10.1016/j.iccn.2015.09.001.
[26] 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. https://doi.org/10.1111/nicc.12326.
[27] Mesukko J, Turale S, Jintrawet U, Niyomkar S. 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.
[28] Carnevale FA, Farrell C, Cremer R, Canoui P, Seguret S, Gaudreault J, 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. https://doi.org/10.1177/1367493511420184.
[29] 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. https://doi.org/10.1111/nin.12437.
[30] Poompan P, Fongkaew W, Mesukko J, Niyomkar S. 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.

[31] LaFond CM, Vincent CVH, Oosterhouse K, Wilkie DJ. Nurses' Beliefs Regarding Pain in Critically Ill Children: A Mixed-Methods Study. J Pediatr Nurs 2016;31:691–700. https://doi.org/10.1016/j.pedn.2016.08.002.
[32] LaFond CM, Van Hulle Vincent C, Corte C, Hershberger PE, Johnson A, Park CG, et al. PICU Nurses' Pain Assessments and Intervention Choices for Virtual Human and Written Vignettes. J Pediatr Nurs 2015;30:580–90. https://doi.org/10.1016/j.pedn.2015.01.022.
[33] 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. https://doi.org/10.1177/1367493511406566.
[34] Mattsson J, Meijers J, Björling G. Challenges in Nursing Care of Children With Substance Withdrawal Syndrome in the PICU. SAGE Open Nurs 2022;8:1–7. https://doi.org/10.1177/23779608221117382.
[35] Craske J, Carter B, Jarman IH, Tume LN. Nursing judgement and decision-making using the Sedation Withdrawal Score (SWS) in children. J Adv Nurs 2017;73:2327–38. https://doi.org/10.1111/jan.13305.
[36] Bower RA, Coad JE, Manning JC, Pengelly TA. 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. https://doi.org/10.1016/j.iccn.2017.04.012.
[37] Zheng K, Sarti A, Boles S, Cameron S, Carlisi R, Clark H, et al. Impressions of early mobilization of critically ill children—clinician, patient, and family perspectives. Pediatr Crit Care Med 2018;19:e350–7. https://doi.org/10.1097/PCC.0000000000001547.
[38] Deja E, Roper L, Tume LN, Dorling J, Gale C, Arch B, 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. https://doi.org/10.1186/s40814-021-00784-5.
[39] Schults JA, Cooke M, Long D, Mitchell ML. "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. https://doi.org/10.1016/j.aucc.2018.03.002.
[40] Frechette J, Bitzas V, Kilpatrick K, Aubry M, Lavoie-Tremblay M. A hermeneutic–phenomenological study of paediatric intensive care unit nurses' professional identity following hospital redesign: Lessons learned for managers. J Nurs Manag 2020b;28:872–80. https://doi.org/10.1111/jonm.13012.
[41] 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. https://doi.org/10.1097/CNQ.0b013e3181f64979.
[42] 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. https://doi.org/10.1016/j.iccn.2013.08.002.
[43] Burton M, Caswell H, Porter C, Mott S, DeGrazia M. 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. https://doi.org/10.1097/DCC.0000000000000403.

[44] Geoghegan S, Oulton K, Bull C, Brierley J, Peters M, Jo Wray, et al. The Challenges of Caring for Long-Stay Patients in the PICU. Pediatr Crit Care Med 2016;17:e266–71. https://doi.org/10.1097/PCC.0000000000000725.
[45] Stayer D, Lockhart JS. Living with Dying in the Pediatric Intensive Care Unit: A Nursing Perspective. Am J Crit Care 2016;25:350–6. https://doi.org/10.4037/ajcc2016251.
[46] Buckley, Berta, Cleverley, Widger. Exploring Pediatric Nurses' Perspectives on Their Work Environment, Work Attitudes, and Experience of Burnout: What Really Matters? Front Pediatr 2022;10:851001. https://doi.org/10.3389/fped.2022.851001.
[47] Wei H, Kifner H, Dawes ME, Wei TL, Boyd JM. Self-care strategies to combat burnout among pediatric critical care nurses and physicians. Crit Care Nurse 2020;40:44–53. https://doi.org/10.4037/ccn2020621.
[48] Michelson KN, Patel R, Haber-Barker N, Emanuel L, Frader J. End-of-life care decisions in the pediatric intensive care unit: roles professionals play. Pediatr Crit Care Med 2013;14:e34–44. https://doi.org/10.1097/PCC.0b013e31826e7408.
[49] Birchley G, Gooberman-Hill R, Deans Z, Fraser J, Huxtable R. 'Best interests' in paediatric intensive care: an empirical ethics study. Arch Dis Child 2017;102:930–5. https://doi.org/10.1136/archdischild-2016-312076.
[50] Watson AC, October TW. Clinical Nurse Participation at Family Conferences in the Pediatric Intensive Care Unit. Am J Crit Care 2016;25:489–97. https://doi.org/doi:10.4037/ajcc2016817.
[51] Walter JK, Sachs E, Schall TE, Dewitt AG, Miller VA, Arnold RM, et al. Interprofessional Teamwork During Family Meetings in the Pediatric Cardiac Intensive Care Unit. J Pain Symptom Manage 2019;57:1089–98. https://doi.org/10.1016/j.jpainsymman.2019.03.002.
[52] 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. https://doi.org/10.1016/j.iccn.2019.07.004.
[53] Carnevale FA, Benedetti M, Bonaldi A, Bravi E, Trabucco G, Biban P. Understanding the private worlds of physicians, nurses, and parents: A study of life-sustaining treatment decisions in Italian paediatric critical care. J Child Health Care 2011;15:334–49. https://doi.org/10.1177/1367493511420183.
[54] Kahveci R, Ayhan D, Doner P, Cihan FG, Koc EM. Shared decision-making in pediatric intensive care units: a qualitative study with physicians, nurses and parents. Indian J Pediatr 2014;81:1287–92. https://doi.org/10.1007/s12098-014-1431-6.
[55] Michelson KN, Emanuel L, Carter A, Brinkman P, Clayman ML, Frader J. 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. https://doi.org/10.1097/PCC.0b013e3182192a98.
[56] Long DA, Young J, Rickard CM, Mitchell ML. Analysing the role of the PICU nurse to guide education of new graduate nurses. Nurse Educ Today 2013;33:388–95. https://doi.org/10.1016/j.nedt.2013.01.016.
[57] 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. https://doi.org/10.1111/j.1471-6712.2010.00819.x.

[58] Tume LN, Kneyber MCJ, Blackwood B, Rose L. Mechanical Ventilation, Weaning Practices, and Decision Making in European PICUs*: Pediatr Crit Care Med 2017;18:e182–8. https://doi.org/10.1097/PCC.0000000000001100.

[59] Tume LN, Latten L, Kenworthy L. Paediatric intensive care nurses' decision-making around gastric residual volume measurement. Nurs Crit Care 2017;22:293–7. https://doi.org/10.1111/nicc.12304.

[60] Magner C, Valkenburg AJ, Doherty D, van Dijk M, O'Hare B, Segurado R, et al. The impact of introducing nurse-led analgesia and sedation guidelines in ventilated infants following cardiac surgery. Intensive Crit Care Nurs 2020;60:102879–102879. https://doi.org/10.1016/j.iccn.2020.102879.

[61] Sawatzky J-AV, Enns CL, Legare C. Identifying the key predictors for retention in critical care nurses. J Adv Nurs 2015;71:2315–25. https://doi.org/10.1111/jan.12701.

Figure 1: PRISMA Flow Diagram

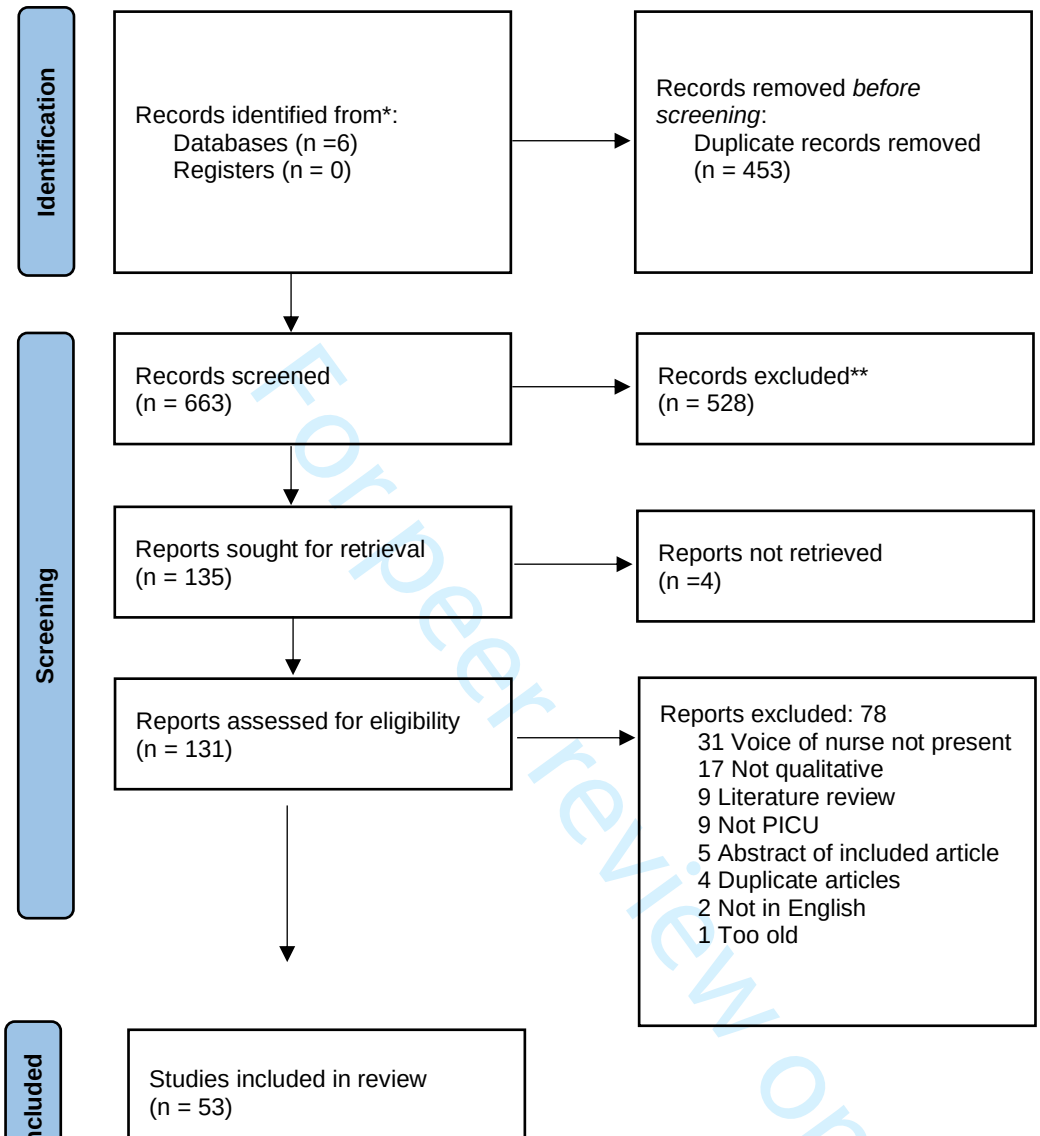

Figure 1: PRISMA Flow Diagram

From: Page. MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71. For more information, visit: http://www.prisma-statement.org/

Appendix 1 Summary of findings

Author, Year	Lead author profession	Country	Publication	Aim	Population & Setting	Methods	Context	Key findings related to voice of nurse
Baird *et al*. (2015)	Nurse	US	Journal of Pediatric Nursing	To explore the impact of hospital and unit-based rules upon patient and family-centred care in PICU	PICU Nurses (n=12) & Parents Single PICU	Interviews & observation	Families and patients in PICU	-Nurses described role as rule enforcer -Not always consistent in enforcing rules -Parents who deviate from expected behaviour labelled as 'difficult'
Baird *et al*. (2016)	Nurse	US	Nursing Research	To explore nurses' views on continuity of care	PICU Nurses (n=12) & Parents Single PICU	Interviews & observation	Families and patients in PICU	-Continuity of care valued by nurses for importance to families, allows nurses to get to know families -Can impact skill maintenance as a result nurses have desire to care for a wide variety of patients -Faces practical challenges including staffing
Birchley *et al.* (2017)	Nurse	UK	Archives of Disease in Childhood	To explore participants' experiences of decision-making in PICU related to child's 'best interests.	PICU Nurses (n=8), parents & MDT Single PICU	Interviews	EoL in PICU	-Nurses introduce snippets of information to families to help parents -Clinicians 'reframe' information to increase parental acceptance -Shared decision-making described as important but no agreement for what it means

Bloomer *et al*. (2015)	Nurse	Australia	Australian Critical Care	To explore how NICU/PICU nurses care for families before and after death	NICU and PICU nurses (n=13) Multiple PICU/NICU	Interviews & focus groups	EoL in PICU	-Nurses role to prepare families for death -They feel that they know families best and use this rapport to support families -Death part of job, -Colleagues identified as a source of support to cope with death
Bloomer *et al*. (2016)	Nurse	Australia	Intensive & Critical Care Nursing	To explore nurses' experiences of caring for children at end of life	NICU and PICU nurses (n=13) Multiple PICU/NICU	Interviews & focus groups	EoL in PICU	-Role change to focus on families as death approaches -Create opportunities to let family be with their child and create memories
Bower *et al*. (2018)	Nurse	UK	Intensive and Critical Care Nursing	To explore nurses' views on interruption during medication administration	PICU nurses (n=10) Single PICU	Interviews & observation	Healthcare delivery	-Nurses felt a need to respond to interruptions -Multi-tasking while doing meds including observing the patient -Increased focus when medication was unfamiliar
Buckley *et al*. (2022)	Nurse	Canada	Frontiers in Pediatrics	To explore paediatric nurses' perspectives on their work environment, work attitudes, and experience of burnout	NICU & PICU Nurses (n=9) PICU/NICU	Interviews	Nursing as a healthcare professional	-Burnout is complex, difficult to self-identify but regularly occurs in nurses. -Burnout also impacts ability to find meaning in work. -Variety of work, acuity of care and team help reduce burnout -Felt that their role differs to other nurses around hospital therefore need different support.
Burton *et*	Nurse	Ca	Dimension	To better understand	NICU & PICU	Focus	Nurse as	-Nurses concerned with quality

***al*. (2020)**		na da	s of Critical Care Nursing	PICU & NICU nurses understanding and experience of moral distress	Nurses (n=57) Multiple PICU/NICU	groups	a healthcare professional	of life of patients and families -Concerns that families don't have adequate information due to communication issues -Nurses input not always valued can lead to moral distress -More moral distress when nurses do not agree with care plans -Some nurses had to leave due to clinical care
Butler *et al*. (2017)	Nurse	Au str alia	Nursing in Critical Care	To explore nurses' perceptions of working with families in the PICU	PICU nurses (n=5) Single PICU	Interviews	Family and patients in PICU	-Role as gatekeeper, not necessarily negative as it supports family's involvement in care provision -Difference caring for chronic vs acute patients -Controlled delivery of information based on perceived ability of families to cope -Act as channel between medical and families for communication -Continuity of care important but variety valued more by nurses
Carnevale et al. (2011)	Nurse	Ital y	Journal of Child Health Care	To understand decision-making around life sustaining treatment in PICU in Italy	PICU Nurses (n=26), parents & MDT Single PICU	Focus groups	EoL in PICU	-Nurses felt excluded from treatment decision-making -Nurses described the important contributions that they could make, given their relationships with parents. -Decisions and care provision contribute to moral distress

Carnevale *et al*. (2012)	Nurse	France & Canada	Journal of Child Health Care	To understand decision-making around life sustaining treatment in PICU in France and Canada	PICU Nurses (n= 24) & Medical team Multiple PICUs	Focus groups	EoL in PICU	-Nurses have in-between role when communicating -Frequently absent from meetings and commonly silent even when present -Often raise life-limiting therapy before medical team
Coats *et al*. (2018)	Nurse	US	American Journal of Critical Care	To explore nurses' perspectives on providing FCC in PICU	NICU & PICU Nurses (n=10) PICU/NICU	Interviews	Family and patient in PICU	-Family presence allows relationship building and nurses give parents jobs to be involved in care -Challenging when parents distract from care provision -Can be stressful having families present -Single rooms better for families but can be isolating for nurses
Craske *et al*. (2017)	Nurse	UK	Journal of Advanced Nursing	To explore nurses' decision-making around sedation withdrawal	PICU Nurses (n=12) Single PICU	Interviews	Healthcare delivery	-Caring for children on consecutive days enhances assessment -Use parents to support assessment to help identify normal behaviour for that child -Sedation weaning score does not support complex thinking involved in decision-making related to weaning
de Weerd *et al*. (2015)	Medical	Netherlands	European Journal of Pediatrics	To explore suffering in children while in PICU	PICU nurses (n=29), parents & MDT Single PICU	Interviews	Healthcare delivery	-Nurses were focused on the signs that caused discomfort and on the treatment of this discomfort -Focused on short-term perspective on suffering

Deja *et al*. (2021)	Researcher	UK	Pilot and Feasibility Studies	To explore parent and practitioner views on the acceptability of the proposed GASTRIC trial	PICU nurses (n=31), parents & MDT Single PICU	Interviews & focus groups	Healthcare delivery	-Nurses concerned over potential change in practice even though limited evidence to support it -Focus in PICU on doing things -Different views from some junior nurses related to trial acceptability
Denis-Larocque *et al.* (2017)	Nurse	Canada	Intensive & Critical Care Nursing	To explore nurses' perceptions of caring for parents of children with chronic medical complexity in the PICU	PICU nurses (n=10) Single PICU	Interviews	Family and patient in PICU	-Challenges due to parent as expert -Need to negotiate care with parents -Takes time to establish relationships
Dopson & Long-Sutehall. (2019)	Nurse	UK	Intensive & Critical Care Nursing	To explore PICU nurses' knowledge, attitudes, and feelings when donation after circulatory death is an option at end of life	PICU Nurses (n=8) Single PICU	Interviews & focus groups	EoL in PICU	-Limited education provided on donation -Nurses may be best placed to have these conversations as they know the patients best but reluctant to do so
Felipin *et al*. (2018)	Nurse	Brazil	Ciencia, Cuidado e Saude	To explore the meaning of family Centered Care	PICU and NICU nurses (n=19) PICU/NICU	Interviews	Families and patients in PICU	-Family extension of patient, aim to involve them in patient care -Believe parents help children recover -Parents gradually learn to provide care to their child in PICU
Foglia *et al*. (2010)	Nurse	US	Critical Care Nursing Quarterly	To explore factors that influence PICU nurses to leave their jobs	PICU Nurses (n=10) Single PICU	Interviews	Nurse as a healthcare professional	-Nurses describe the challenges of caring for sick children as a positive -Insufficient resources and support are stressors -Unrelieved stress as major reason leave job

Frechette *et al*. (2020a)	Nurse	Canada	Nursing in Critical Care	To examine PICU nurses' lived experience of caring for families following a major hospital transformation project.	PICU Nurses (n=15) Single PICU	Interviews & observation	Families and patients in PICU	-Gatekeeping occurs when nurse enforce rules and dictate parental role in care -Value an environment that offers personalised care -Often focused on the child rather than the family
Frechette *et al*. (2020b)	Nurse	Canada	Journal of Nursing Management	To explore nurses' professional identity following a redesign	PICU Nurses (n=15) Single PICU	Interviews & observation	Nurse a healthcare professional	-Reluctance to care for chronic long-term patients due to moral distress and pull from acute patients -Can be challenging to adjust to different care needs for chronic patients eg. Less monitoring -Can result in increased patient load when less acute which is challenging in single rooms
Gagnon & Kunyk (2022)	Nurse	Canada	Nursing Inquiry	To explore the moral distress experiences of PICU nurses caring for child patients who are dying	PICU Nurses (n=7) Multiple PICUs	Interviews	EoL in PICU	-Desire to give children dignified death that was peaceful -Burden of knowledge as an insider but not able to share with families can cause moral distress -Limited ability to be heard in decision-making -Use of language to communicate nurses' perspective -Nurse can experience moral distress when dignity not prioritised
Geoghegan	Resear	UK	Pediatric	To explore the	NICU & PICU	Interview	Families	-Significant impact of caring for

***et al*. (2016)**	cher		Critical Care Medicine	challenges of caring for long-stay patients in the PICU	Nurses (n=7) & MDT Single PICU	s	and patients in PICU	long-stay patients (LSP)- moral distress and low morale -Desire for variety of patients, particularly acute patients -Patients with no long-term plan most challenging
Gonzalez-Gil *et al*. (2021)	Nurse	Spain	Enfermeria Intensiva	To explore nurses' experience related to promoting the visits of siblings to PICU	PICU nurses (n=12) Single PICU	Interviews	Families and patients in PICU	-Emerging demand for sibling visits but no policy -Decisions not documented making consistency difficult -Overall nurses support visits but need to prepare environment to minimise distress
Greenway *et al*. (2019)	Medical	US	Pediatric critical care medicine	To explore barriers to communication in PICU	PICU nurses (n=3), parents & MDT Single PICU	Interviews	Families and patients in PICU	-Breakdown in communication when deviation from plan -Difference in findings from families, limited presentation of voice of nurse.
Henao-Castano & Quinonez-Mora (2019)	Nurse	Colombia	Enferm Intensiva	To explore nurses' coping with death in PICU	PICU nurses (n=10) Single PICU	Interviews	EoL in PICU	-Value of good communication -Focus on care provision at end of life and meaning from work
Ji *et al*. (2022)	Nurse	China	Journal of Nursing Management.	To explore ward and PICU nurses experiences of transferring patients out of PICU	Ward and PICU nurses (n= 14) Single PICU	Focus groups	Healthcare delivery	-Different priorities between ward and PICU nurses -Request for written handover to improve communication
Kahveci *et al*. (2014)	Medical	Turkey	Indian journal of pediatrics	To understand how decisions are made in PICU settings where critically ill children require life-support	PICU nurses (n=9), parents & MDT	Interviews	EoL in PICU	- Should be physician's responsibility to make the decisions in medically critical situations. - Nurses seemed to have more

				decision	Single PICU			understanding of the parents' feelings, compared to the doctors. -Decision-making gets easier with more experience in PICU
LaFond *et al*. (2015)	Nurse	US	Journal of Pediatric Nursing	To explore factors nurses, consider when assessing pain and selecting interventions in PICU	PICU nurses (n=40) Single PICU	Interviews & vignette questionnaires	Healthcare deliv	-PICU nurses used their own assessment over patient reported pain scores
LaFond *et al*. (2016)	Nurse	US	Journal of Pediatric Nursing	To describe PICU nurses' beliefs regarding the assessment and management of children's pain.	PICU nurses (n=40) Single PICU	Interviews & vignette questionnaire	Healthcare deliv	-Nurses use behaviour to describe pain over pain scores -Each patient unique making self-report difficult to rely on -Use experience to guide assessment
Lima *et al*. (2018)	Psychologist	Portugal	Nursing in critical care	To describe PICU nurses experiences with the sudden death of children/adolescents	NICU & PICU (n=36) Nurses Multiple PICU/NICU	Interviews & questionnaire	EoL in PICU	-Sudden death of patients resulted in significant impact on nurses -Experience helped with coping -Limited training and local support for this situation
Mahon (2014)	Nurse	Canada	Intensive and Critical Care Nursing	To explore PICU nurses job satisfaction through an ethnographic view of PICU	PICU Nurses (n=31) Single PICU	Interviews & observation	Nursing as a healthcare professional	-Change in way nurses spoke and communicate with experience -Value on experience and education -Lack of respect and power imbalance contributes to staff leaving -Value in provision of 'good death' doesn't contribute to intent to leave
Mattsson *et al*. (2011)	Nurse	Swed	Journal of Child	To explore nurses' clinical experiences of	PICU Nurses (n=17)	Interviews	Healthcare deliver	-Assessment on patient presentation

		en	Health Care	pain in non-verbal children in the PICU	Single PICU			-Use of experience to measure pain -Need to know patient baseline
Mattsson *et al*. (2022)	Nurse	Sweeden	SAGE Open Nursing	To explore nurses' challenges caring for children with substance withdrawal in the PICU	PICU nurses (n=5) Single PICU	Interviews	Healthcare delivery	-Focus on weaning to child's need not to desire to discharge from PICU -Need for correct language to communicate assessment based on experience
Medeiros *et al*. (2022)	Nurse	Brazil	Revista Brasileira de Enfermagem	To explore staff perceptions of their relationship with families of children during palliative care in PICU	NICU & PICU nurses and nurse technicians* (n=17) PICU/NICU	Interviews	EoL PICU	-Staff impacted by family acceptance of death -Influenced by communication of medical prognosis and false hope -Focus on care needs of child including keeping them pain free and family needs
Mesukko *et al*. (2020)	Nurse	Thailand	Pacific Rim International Journal of Nursing Research	To explore perspective of palliative care in PICU	PICU nurses (n=41) & medical team Multiple PICU/NICU	Interviews & focus groups	EoL PICU	-Communication essential for good pal care -Nurses should be at all planning meetings -Need for continuity of care at EoL -Nurses led symptom management related to EoL
Meyer (2014)	Nurse	US	Journal of Pediatric Nursing	To explore nurses' experiences caring for dying children	PICU Nurses (n=10) Single PICU	Interviews	EoL in PICU	-Difference in caring for children who are expected to die versus those who die unexpectedly in the same shift -When nurses realise approach of death, anxiety occurs until family updated -Step back emotionally from situation -Nurses provide care physically

								and medically and focus on creating order in the chaos
Meyer *et al*. (2012)	Nurse	US	Pediatric Critical Care Medicine	To explore practitioners' response to parents asking, 'what would you do if this is your child?' during simulation in PICU	PICU nurses (n=13) & MDT Single PICU	Simulation & interviews	EoL in PICU	-Focus on providing clinical information -Varied responses from practitioners including sharing personal information -Nurses focus on offering support
Michelson *et al*. (2011)	Medical	US	Pediatric Critical Care Medicine	To explore the processes used in EoL decision-making and the roles in family conferences (FC)	PICU nurses (n=23), parents & MDT Single PICU	Interviews & focus groups	EoL in PICU	-FC used to coordinate care and for communication -Nurses act as advocates -Nurses often asked questions after meeting even when not there -Nurses often absent due to competing demands
Michelson and Patel *et al*. (2013)	Medical	US	Pediatric Critical Care Medicine	To explore roles at end-of-life care	PICU nurses (n=23), parents & MDT Single PICU	Interviews & focus groups	EoL in PICU	-Nurses often act as family supporter and advocate -Information mainly given by medical team -Nurses often play role of secondary decision maker by censoring information given to families
Mitchell & Dale (2015)	Medical	UK	Palliative Medicine	To explore views regarding advance care planning (ACP) in pal care in PICU	PICU nurses (n=6) & medical team Single PICU	Interviews	EoL in PICU	-Failure to recognise approach of death stops ACP in practice -Nurses often recognise approach of EoL first -Considered good idea but needs MDT involvement -Moral distress when not acting in best interest of patient
Nilson *et al*. (2022)	Nurse	Brazil	Inquiry	To explore nurses' experience of the	PICU Nurses (n=25)	Interviews	EoL in PICU	-Research allowed nurses an opportunity to discuss this

				decision-making process related to therapeutic support limitation in PICU	Multiple PICUs			issue where they normally don't have voice -Predominantly mediator in decision-making -Feelings of frustration from exclusion
Park & Oh (2022)	Nurse	Korea	Child Health Nursing Research	To explore nurses and mothers' perceptions of partnership in PICU	PICU nurses (n=12) & Parents Single PICU	Interviews	Family and patient in PICU	-Differing views on partnership, nurses believe unequal due to knowledge imbalance -Focus on clinical care, reluctance to deliver information
Poompan *et al*. (2020)	Nurse	Thailand	Pacific Rim International Journal of Nursing Research	To explore experiences of EoL care in a Thai PICU	PICU nurses (n=24) & Parents Single PICU	Interviews & observation	EoL in PICU	-Nurses had to wait for medical team to redirect care before providing EoL care -Once change to comfort nurses lead care and support parents to make decisions and provide care -Nurses coordinate communication
Soares *et al*. (2020)	Nurse	Brazil	Revista Brasileira de Enfermagem	To explore nurses' perceptions of comfort in PICU	PICU nurses (n=40) and nurse technicians* Single PICU	Interviews	Healthcare delivery	-Nurses aim to promote comfort -Includes environmental for example noise and care specific including pain interventions
Schults *et al*. (2019)	Nurse	Australia	Australian Critical Care	To explore nursing practice of suctioning in PICU	PICU nurses (n=12) Single PICU	Interviews	Healthcare delivery	-Nurses use experience to decide suctioning practice -Aware of lack of research- they rely on own practice
Stayer & Lockhart (2020)	Nurse	US	American Journal of Critical	To explore PICU nurses' ability to cope with death	PICU nurses (n=12)	Interviews	EoL in PICU	-Death part of the job but its emotionally demanding -Focus on providing peaceful

			Care		Single PICU			end of children -Very hard when hope taken away but harder when reluctance to talk about death by medical team
van den Bos-Boon *et al*. (2021)	Nurse	Netherlands	Journal of Pediatric Nursing	To explore the effectiveness of sim training in resus skills	PICU nurses (n=19) Single PICU	Interviews & simulation observation	Nurse as a healthcare professional	-Sim training increased nurses' confidence in resus skills -Nurses had limited recognition of improvement of leadership communication during sim (traditionally medical led)
Vance *et al*. (2020)	Nurse	US	Advances in Neonatal Care	To explore perspectives in facilitating FCC	NICU & PICU Nurses (n=10) & Medical PICU/NICU	Interviews	Family and patients in PICU	-FCC nurse dependent -To promote FCC, they focused on communication to get everyone on same page -Decision-making happens ongoing not at a point in time -Unit design impacts FCC
Walter *et al*. (2019)	Medical	US	Journal of Pain and Symptom Management	To assess teamwork and communication with parents during family meetings.	PICU nurses (n=11) & medical Single PICU	Observation & Survey	Families and patients in PICU	-Nurses' contribution focused on providing medical information related to care at the bedside -They offered support and clarified elements for families
Watson & October (2016)	Nurse	US	American Journal of Critical Care	To explore clinical nurse participation in family meetings	PICU nurses (47 survey & nurses in meetings) Single PICU	Observation & survey	Families and patients in PICU	-A clinical nurse attended 20 (50%) of the family conferences that were audio-recorded but only made contribution in 25% of them. -Unable to attend due to clinical demands -Being present allows them to be present to hear news firsthand -nurses who did not speak said

								they had wanted to speak, and some of the reasons provided were that they were "uncomfortable speaking," "were not asked"
Wei *et al*. (2020)	Nurse	US	Critical Care Nurse	To explore self-care to prevent burnout for staff in PICU	PICU nurses (n=13) & Medical Single PICU	Interviews	Nurse as a healthcare professional	-Finding meaning in work kept staff motivated -Support from colleagues important
Zheng *et al*. (2018)	Researcher	Canada	Pediatric Critical Care Medicine	To explore impressions of early mobilization of critically ill children	PICU nurses (n=10), parents & MDT Single PICU	Interviews	Healthcare delivery	-Early mobility important but not a priority -Felt like they had responsibility, but it increased workload

BMJ Open

The voice of the nurse in paediatric intensive care: a scoping review

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2023-082175.R3
Article Type:	Original research
Date Submitted by the Author:	31-Oct-2024
Complete List of Authors:	Masterson, Kate; University College Dublin, School of Nursing, Midwifery and Health Systems; Murdoch Children's Research Institute, Paediatric Intensive Care Unit Connolly, Michael; University College Dublin, Schoool of Nursing, Midwifery and Health Systems Alexander, Denise; University College Dublin, Schoool of Nursing, Midwifery and Health Systems Brenner, Maria; University College Dublin, School of Nursing, Midwifery & Health Systems
Primary Subject Heading:	Nursing
Secondary Subject Heading:	Paediatrics, Intensive care, Qualitative research
Keywords:	Nurses, Decision Making, Paediatric intensive & critical care < ANAESTHETICS, Child

I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our licence.

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which Creative Commons licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

Title: The voice of the nurse in paediatric intensive care: a scoping review

Kate Masterson[1,2], Michael Connolly[1], Densie Alexander[1], Maria Brenner[1]

1. University College Dublin, School of Nursing, Midwifery and Health Systems
Dublin, Ireland

2. Murdoch Children's Research Institute, Paediatric Intensive Care Unit
Parkville, VIC, Australia

Corresponding author:

Full name Kate Masterson

Contact: School of Nursing, Midwifery and Health Systems, University College Dublin,

Dublin 4, Ireland.

E-mail: kate.masterson@ucdconnect.ie

Keywords “Paediatric Intensive Care” “nurse” “decision-making” “communication” “scoping review”

Word count 4198

Abstract

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

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

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 programme NVIVO 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 in 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.

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 PICU.

-This review highlighted key areas 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.

Funding This project has received funding from the European Research Council under the European Union's Horizon 2020 research and innovation programme (grant agreement no. 803051).

Patient or Public Contribution No patient or public contribution as the primary author was a member of the relevant group (PICU nurses) and guided the review.

Competing interests None declared.

Introduction

The concept of voice is discussed in many contexts within healthcare literature, focusing on research participant perspectives to inform and improve clinical practice, education and policy, and to identify future research needs [1]. 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 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 [7]. In paediatrics nurses are the healthcare professionals with the most contact with families, and are thus best positioned to support family presence and participation in care decisions [8]. Despite the pivotal role nurses play in care provision and communicating with families, their voices are underrepresented in the scientific literature in 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 (Munn et al. 2018). 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 underrepresented 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 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.

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 (2005) and further developed by Levac et al. (2010) [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 were 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 into a concept it is restricted by pre-defined variables and research tools aimed at extracting numerical data to better understand the concept [1].

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 programme NVIVO 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 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 were included. Any research that described care of paediatric critical care patients were 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 supplementary table.
Step 6 Consultation (optional)	They 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 H, O'Malley L. Scoping studies: towards a methodological framework. International Journal of Social Research Methodology 2005;8:19–32. https://doi.org/10.1080/1364557032000119616.*

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

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 NICUs 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.

Table 3: General characteristics of the articles included

Characteristic	Number (n=53)
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 & survey	2 (4%)
Country	
United States	16 (30%)
Canada	8 (15%)
Europe (including the UK)	15 (28%)
South America	5 (10%)
Australia	4 (7.5%)
Asia	4 (7.5%)
Multi-country	1 (2%)
Location	
Single PICU	40 (75%)
Single hospital PICU and NICU	5 (9.5%)
Multiple PICUs	3 (6%)

Table 4: Contexts of findings

Context	Reference
Families and patients in PICU	Baird *et al.*, 2015, 2016; Butler *et al.*, 2017; Coats *et al.*, 2018; Denis-Larocque *et al.*, 2017; Felipin *et al.*, 2018; Frechette *et al.*, 2020; Geoghegan *et al.*, 2016; Gonzalez-Gil *et al.*, 2021; Greenway *et al.*, 2019; Park and Oh, 2022; Vance *et al.*, 2020; Walter *et al.*, 2019; Watson and October, 2016
EOL in PICU	Birchley *et al.*, 2017; Bloomer *et al.*, 2015, 2016; Carnevale *et al.*, 2011, 2012; Dopson and Long-Sutehall, 2019; Gagnon and Kunyk, 2022; Henao-Castaño and Quiñonez-Mora, 2019; Kahveci *et al.*, 2014; Lima *et al.*, 2018; Medeiros *et al.*, 2022; Mesukko *et al.*, 2020; Meyer *et al.*, 2012; Meyer, 2014; Michelson *et al.*, 2011, Michelson and Patel *et al.*, 2013; Mitchell and Dale, 2015; Nilson *et al.*, 2022; Poompan *et al.*, 2020; Stayer and Lockhart, 2016
Healthcare delivery	Bower *et al.*, 2018; Craske *et al.*, 2017; De Weerd *et al.*, 2015; Deja *et al.*, 2021; Ji *et al.*, 2022; LaFond *et al.*, 2015, 2016; Mattsson *et al.*, 2022, 2011; Soares *et al.*, 2020; Schults *et al.*, 2019; Zheng *et al.*, 2018
Nurse as a healthcare professional	Buckley *et al.*, 2022; Burton *et al.*, 2020; Foglia *et al.*, 2010; Frechette *et al.*, 2020b; Mahon, 2014; van den Bos-Boon *et al.*, 2021; Wei *et al.*, 2020

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 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]. 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 [15,17]. 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 [8,17].

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 [17]. The delivery of FCC was described as healthcare professionals giving families a plan of care which aims to manage care delivery [17]. 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]. Gonzalez-Gil et al. (2021) also noted that there was an increased parental desire to include siblings in PICU visitation, though a lack of protocol to support it [18].

Baird et al., (2015) 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 [19]. As a result, they became pseudo-gatekeepers, 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 (2022) 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 [20]. As a result, nurses frequently 'managed' parents through limiting information given to reduce anxiety for parents and limiting participation if they felt parental presence impeded clinical care. Similarly, Felipin et al. (2018) suggested 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 with care provision when they were reluctant to do so [21]. 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 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' [22]. Baird et al., (2016) 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 for families in providing continuity; however, they also voiced that delivering this care impacted skill maintenance and their well-being [23].

Death and providing care at EOL was identified as part of working in PICU, this can be sudden or expected [24–26]. 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 [27]. Mitchell and Dale (2015) identified the lack of recognition of a child's illness as life-limiting as the biggest barrier for initiating the discussion of palliation [24]. These discussions on palliation facilitate a redirection of care focused on the comfort of the child rather than interventions to prolong life [27]. Nurses identified themselves as the health profession who recognised deterioration of children most frequently [24,28]. 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 [29]. Bloomer et al. (2016) found that the nursing role changed when care was re-directed towards palliation, nurses increased their focus on the family, and created opportunities for them to be with their child [25]. Nurses frequently valued continuity of care in this context despite not always supporting it [2,30].

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 [31–33]. 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. (2022) explored nursing perspectives of withdrawing from sedation [34]. They faced a 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., (2017) described nursing experience as a key factor in the assessment of withdrawal from sedation, though it was further enhanced by continuity of care [35].

In other areas of care delivery, Bower et al., (2018) 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 [36]. Two further studies explored views of research interventions noting nursing involvement in research planning impacted their engagement with the projects [37,38]. An Australian study explored nursing experiences of suctioning practices in PICU [39]. 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 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 in working in PICU and this concept influenced their intent to leave [40]. Nurses voiced a negative personal impact of caring for children who are chronically critically ill, compared to a positive impact from caring for children they described as high acuity [40]. This drive for obtaining clinical skills to care for high acuity children was portrayed as a central factor in a PICU nurse's identity. Foglia et al. (2010) 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 [41]. Mahon (2014) noted that this contributed to nurses' likelihood to stay in PICU as they become expert in PICU nursing [42]. 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 (2020) 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 [43]. This included when the nurse felt the child had a poor quality of life. Gagnon and Kunyk (2022) 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 [29]. Geoghegan et al., (2016) 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 [44]. Stayer and Lockhart (2016) noted that there was increased distress for the nurses, if the child had a life-long illness leading to death, rather than death occurring after a shorter illness [45]. Burnout was also prevalent in PICU nurses, with most nurses experiencing burnout at some point although it is difficult to self-identify [46]. Burnout 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. (2020) 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 increased resilience[47].

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 pre-dominantly 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 [28]. Though, Michelson et al., (2013) suggested that the nurses primarily identify their role as that of family supporter and advocate, not as communicator [48]. The concept of gatekeeping was evident in communication with families [21]. 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 [49]. 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 [50,51]. 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 [27]. 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 [52]. However, competing clinical demands do not always allow the nurse to be present at the meetings.

While many studies suggested that shared decision-making occurred, there was a significant variation in the nurses' participation in this process impacted by many factors including context and patient. Carnevale et al. (2011) explored decision-making to sustain life, noting that physicians felt that nurses should not be responsible for making the decisions related to the possibility of death [53]. Similarly, Kahveci et al. (2014) 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 [54]. Nurses acknowledged their role in the team particularly their relationship with families, however, they felt it was not their place to make decisions [54]. Despite this nurses suggested that while they felt they

did not have a responsibility in decision-making, they had a responsibility in care delivery [28]. Nurses raised concerns that they struggle 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 [53]. Nurses believed that their input can lead to greater consistency in decision-making, and ensures the child and families 'best-interests' are considered [53].

The literature also identified 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 need permission to speak [28,50]. 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 [28,55].

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 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 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 [21]. This is particularly pertinent due to the increase in children with PCCI and their frequent re-admissions 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 supports 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 [40–42]. 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 [23,40]. 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 [56]. 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-MDT relationship. Within the nurse-MDT relationship, as nurses gained more experience and became 'expert' in critical care they are more comfortable expressing themselves and feel increased respect from the medical team [42]. Although this level of expertise was described as a technical skill rather than an inter-professional skill [23]. Nurses who had more experience in high acuity care used their experience to adapt to limitations of research supporting care such as suctioning [39] and patient assessment [31,33]. 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 [21,49].

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 [53]. 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 [57]. This is reflective of PICU nurses' increased involvement in ventilation weaning, feeding and sedation management [35,58–60]. 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 [61]. 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.

Statements

Data availability statement Data sharing not applicable – no new data generated, all articles available from source.

Ethical approval statement An ethics statement is not applicable because this study is based exclusively on published literature.

Contributorship statement 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.

Figure legend

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).

References

[1] Polit DF, Beck. Nursing research : generating and assessing evidence for nursing practice. 11th ed. Philadelphia: Wolters Kluwer Health; 2021.

[2] Medeiros JA de, Almeida Júnior JJ, Oliveira LPBA de, Silva FRS da, Silva CC dos S, Barros WCT dos. Death and dying of newborns and children: relationships between nursing and family according to Travelbee. Rev Bras Enferm 2022;75:1–8. https://doi.org/10.1590/0034-7167-2021-0007.

[3] Nilson, Vieira, de Moura Bubadue, Stein, Lago. Decision-Making Process for the Implementation of the Child Therapeutic Support Limitation Plan: Nurses' Experiences. Inq J Med Care Organ Provis Financ 2022;59:469580221100777. https://doi.org/10.1177/00469580221100777.

[4] Cole C, Wellard S, Mummery J. Problematising autonomy and advocacy in nursing. Nurs Ethics 2014;21:576–82. https://doi.org/10.1177/0969733013511362.

[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. https://doi.org/10.1111/scs.12057.

[6] Nsiah C, Siakwa M, Ninnoni JPK. Registered Nurses' description of patient advocacy in the clinical setting. Nurs Open 2019;6:1124–32. https://doi.org/10.1002/nop2.307.

[7] McMillan K, Perron A. Nurses' engagement with power, voice and politics amidst restructuring efforts. Nurs Inq 2020;27:e12345. https://doi.org/10.1111/nin.12345.

[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;23:2086–100. https://doi.org/10.1111/jocn.12498.

[9] Arksey H, O'Malley L. Scoping studies: towards a methodological framework. Int J Soc Res Methodol 2005;8:19–32. https://doi.org/10.1080/1364557032000119616.

[10] Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. Implement Sci 2010;5:69. https://doi.org/10.1186/1748-5908-5-69.

[11] Kalu F, Bwalya J. What Makes Qualitative Research Good Research? An Exploratory Analysis of Critical Elements. Int J Soc Sci Res 2017;5. https://doi.org/10.5296/ijssr.v5i2.10711.

[12] Smith GD, Gelling L, Haigh C, Barnason S, Allan H, Jackson D. The position of reporting guidelines in qualitative nursing research. J Clin Nurs 2018;27:889–91. https://doi.org/10.1111/jocn.14213.

[13] O'Neill M, Booth S, Lamb J. Using NVivo™ for Literature Reviews: The Eight Step Pedagogy (N7+1). Qual Rep 2018. https://doi.org/10.46743/2160-3715/2018.3030.

[14] Baird J, Davies B, Hinds PS, Baggott C, Rehm RS. 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. https://doi.org/10.1016/j.pedn.2014.10.001.

[15] Coats H, Bourget E, Starks H, Lindhorst T, Saiki-Craighill S, Curtis JR, 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. https://doi.org/10.4037/ajcc2018353.

[16] Felipin LCS, Merino M, Baena JA, Oliveira R, Borghesan NBA, Higarashi IH. Family-centered care in neonatal and pediatric intensive care unit: nurse's vision. Cienc Cuid Saude 2018:1–7. https://doi.org/10.4025/cienccuidsaude.v17i2.41001.

[17] 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.
[18] Gonzalez-Gil MT, Alcolea-Cosin MT, Perez-Garcia S, Luna-Castano P, Torrent-Vela S, Gil-Dominguez S, et al. Children's visits to the paediatric intensive care unit from the nurses' experience. Enferm Intensiva 2021;32:133–44. https://doi.org/10.1016/j.enfie.2020.06.002.
[19] Frechette J, Lavoie-Tremblay M, Kilpatrick K, Bitzas V. When the paediatric intensive care unit becomes home: A hermeneutic-phenomenological study. Nurs Crit Care 2020a;25:140–8. https://doi.org/10.1111/nicc.12491.
[20] 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. https://doi.org/10.4094/chnr.2022.28.3.197.
[21] 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. https://doi.org/10.1111/nicc.12142.
[22] Denis-Larocque G, Williams K, St-Sauveur I, Ruddy M, Rennick J. 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. https://doi.org/10.1016/j.iccn.2017.01.010.
[23] Baird J, Rehm RS, Hinds PS, Baggott C, Davies B. Do You Know My Child? Continuity of Nursing Care in the Pediatric Intensive Care Unit. Nurs Res 2016;65:142–50. https://doi.org/10.1097/NNR.0000000000000135.
[24] 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. https://doi.org/10.1177/0269216315573000.
[25] Bloomer MJ, Endacott R, Copnell B, O'Connor M. "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. https://doi.org/10.1016/j.iccn.2015.09.001.
[26] 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. https://doi.org/10.1111/nicc.12326.
[27] Mesukko J, Turale S, Jintrawet U, Niyomkar S. 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.
[28] Carnevale FA, Farrell C, Cremer R, Canoui P, Seguret S, Gaudreault J, 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. https://doi.org/10.1177/1367493511420184.
[29] 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. https://doi.org/10.1111/nin.12437.
[30] Poompan P, Fongkaew W, Mesukko J, Niyomkar S. 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.

[31] LaFond CM, Vincent CVH, Oosterhouse K, Wilkie DJ. Nurses' Beliefs Regarding Pain in Critically Ill Children: A Mixed-Methods Study. J Pediatr Nurs 2016;31:691–700. https://doi.org/10.1016/j.pedn.2016.08.002.
[32] LaFond CM, Van Hulle Vincent C, Corte C, Hershberger PE, Johnson A, Park CG, et al. PICU Nurses' Pain Assessments and Intervention Choices for Virtual Human and Written Vignettes. J Pediatr Nurs 2015;30:580–90. https://doi.org/10.1016/j.pedn.2015.01.022.
[33] 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. https://doi.org/10.1177/1367493511406566.
[34] Mattsson J, Meijers J, Björling G. Challenges in Nursing Care of Children With Substance Withdrawal Syndrome in the PICU. SAGE Open Nurs 2022;8:1–7. https://doi.org/10.1177/23779608221117382.
[35] Craske J, Carter B, Jarman IH, Tume LN. Nursing judgement and decision-making using the Sedation Withdrawal Score (SWS) in children. J Adv Nurs 2017;73:2327–38. https://doi.org/10.1111/jan.13305.
[36] Bower RA, Coad JE, Manning JC, Pengelly TA. 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. https://doi.org/10.1016/j.iccn.2017.04.012.
[37] Zheng K, Sarti A, Boles S, Cameron S, Carlisi R, Clark H, et al. Impressions of early mobilization of critically ill children—clinician, patient, and family perspectives. Pediatr Crit Care Med 2018;19:e350–7. https://doi.org/10.1097/PCC.0000000000001547.
[38] Deja E, Roper L, Tume LN, Dorling J, Gale C, Arch B, 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. https://doi.org/10.1186/s40814-021-00784-5.
[39] Schults JA, Cooke M, Long D, Mitchell ML. "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. https://doi.org/10.1016/j.aucc.2018.03.002.
[40] Frechette J, Bitzas V, Kilpatrick K, Aubry M, Lavoie-Tremblay M. A hermeneutic–phenomenological study of paediatric intensive care unit nurses' professional identity following hospital redesign: Lessons learned for managers. J Nurs Manag 2020b;28:872–80. https://doi.org/10.1111/jonm.13012.
[41] 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. https://doi.org/10.1097/CNQ.0b013e3181f64979.
[42] 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. https://doi.org/10.1016/j.iccn.2013.08.002.
[43] Burton M, Caswell H, Porter C, Mott S, DeGrazia M. 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. https://doi.org/10.1097/DCC.0000000000000403.

[44] Geoghegan S, Oulton K, Bull C, Brierley J, Peters M, Jo Wray, et al. The Challenges of Caring for Long-Stay Patients in the PICU. Pediatr Crit Care Med 2016;17:e266–71. https://doi.org/10.1097/PCC.0000000000000725.
[45] Stayer D, Lockhart JS. Living with Dying in the Pediatric Intensive Care Unit: A Nursing Perspective. Am J Crit Care 2016;25:350–6. https://doi.org/10.4037/ajcc2016251.
[46] Buckley, Berta, Cleverley, Widger. Exploring Pediatric Nurses' Perspectives on Their Work Environment, Work Attitudes, and Experience of Burnout: What Really Matters? Front Pediatr 2022;10:851001. https://doi.org/10.3389/fped.2022.851001.
[47] Wei H, Kifner H, Dawes ME, Wei TL, Boyd JM. Self-care strategies to combat burnout among pediatric critical care nurses and physicians. Crit Care Nurse 2020;40:44–53. https://doi.org/10.4037/ccn2020621.
[48] Michelson KN, Patel R, Haber-Barker N, Emanuel L, Frader J. End-of-life care decisions in the pediatric intensive care unit: roles professionals play. Pediatr Crit Care Med 2013;14:e34–44. https://doi.org/10.1097/PCC.0b013e31826e7408.
[49] Birchley G, Gooberman-Hill R, Deans Z, Fraser J, Huxtable R. 'Best interests' in paediatric intensive care: an empirical ethics study. Arch Dis Child 2017;102:930–5. https://doi.org/10.1136/archdischild-2016-312076.
[50] Watson AC, October TW. Clinical Nurse Participation at Family Conferences in the Pediatric Intensive Care Unit. Am J Crit Care 2016;25:489–97. https://doi.org/doi:10.4037/ajcc2016817.
[51] Walter JK, Sachs E, Schall TE, Dewitt AG, Miller VA, Arnold RM, et al. Interprofessional Teamwork During Family Meetings in the Pediatric Cardiac Intensive Care Unit. J Pain Symptom Manage 2019;57:1089–98. https://doi.org/10.1016/j.jpainsymman.2019.03.002.
[52] 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. https://doi.org/10.1016/j.iccn.2019.07.004.
[53] Carnevale FA, Benedetti M, Bonaldi A, Bravi E, Trabucco G, Biban P. Understanding the private worlds of physicians, nurses, and parents: A study of life-sustaining treatment decisions in Italian paediatric critical care. J Child Health Care 2011;15:334–49. https://doi.org/10.1177/1367493511420183.
[54] Kahveci R, Ayhan D, Doner P, Cihan FG, Koc EM. Shared decision-making in pediatric intensive care units: a qualitative study with physicians, nurses and parents. Indian J Pediatr 2014;81:1287–92. https://doi.org/10.1007/s12098-014-1431-6.
[55] Michelson KN, Emanuel L, Carter A, Brinkman P, Clayman ML, Frader J. 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. https://doi.org/10.1097/PCC.0b013e3182192a98.
[56] Long DA, Young J, Rickard CM, Mitchell ML. Analysing the role of the PICU nurse to guide education of new graduate nurses. Nurse Educ Today 2013;33:388–95. https://doi.org/10.1016/j.nedt.2013.01.016.
[57] 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. https://doi.org/10.1111/j.1471-6712.2010.00819.x.

[58] Tume LN, Kneyber MCJ, Blackwood B, Rose L. Mechanical Ventilation, Weaning Practices, and Decision Making in European PICUs*: Pediatr Crit Care Med 2017;18:e182–8. https://doi.org/10.1097/PCC.0000000000001100.

[59] Tume LN, Latten L, Kenworthy L. Paediatric intensive care nurses' decision-making around gastric residual volume measurement. Nurs Crit Care 2017;22:293–7. https://doi.org/10.1111/nicc.12304.

[60] Magner C, Valkenburg AJ, Doherty D, van Dijk M, O'Hare B, Segurado R, et al. The impact of introducing nurse-led analgesia and sedation guidelines in ventilated infants following cardiac surgery. Intensive Crit Care Nurs 2020;60:102879–102879. https://doi.org/10.1016/j.iccn.2020.102879.

[61] Sawatzky J-AV, Enns CL, Legare C. Identifying the key predictors for retention in critical care nurses. J Adv Nurs 2015;71:2315–25. https://doi.org/10.1111/jan.12701.

Figure 1: PRISMA Flow Diagram

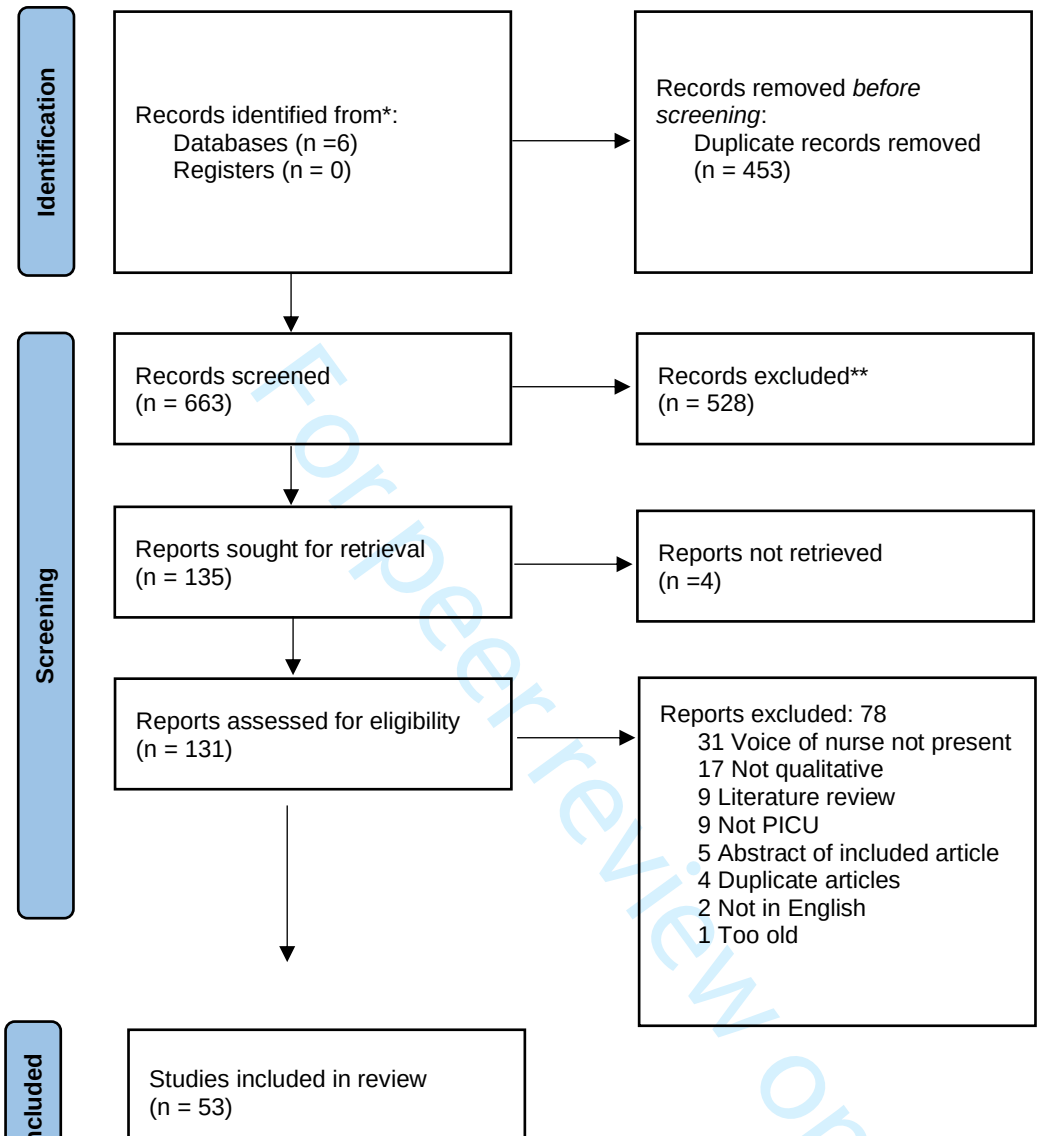

Figure 1: PRISMA Flow Diagram

From: Page. MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71. For more information, visit: http://www.prisma-statement.org/

Appendix 1 Summary of findings

Author, Year	Lead author profession	Country	Publication	Aim	Population & Setting	Methods	Context	Key findings related to voice of nurse
Baird *et al*. (2015)	Nurse	US	Journal of Pediatric Nursing	To explore the impact of hospital and unit-based rules upon patient and family-centred care in PICU	PICU Nurses (n=12) & Parents Single PICU	Interviews & observation	Families and patients in PICU	-Nurses described role as rule enforcer -Not always consistent in enforcing rules -Parents who deviate from expected behaviour labelled as 'difficult'
Baird *et al*. (2016)	Nurse	US	Nursing Research	To explore nurses' views on continuity of care	PICU Nurses (n=12) & Parents Single PICU	Interviews & observation	Families and patients in PICU	-Continuity of care valued by nurses for importance to families, allows nurses to get to know families -Can impact skill maintenance as a result nurses have desire to care for a wide variety of patients -Faces practical challenges including staffing
Birchley *et al.* (2017)	Nurse	UK	Archives of Disease in Childhood	To explore participants' experiences of decision-making in PICU related to child's 'best interests.	PICU Nurses (n=8), parents & MDT Single PICU	Interviews	EoL in PICU	-Nurses introduce snippets of information to families to help parents -Clinicians 'reframe' information to increase parental acceptance -Shared decision-making described as important but no agreement for what it means

Bloomer *et al*. (2015)	Nurse	Australia	Australian Critical Care	To explore how NICU/PICU nurses care for families before and after death	NICU and PICU nurses (n=13) Multiple PICU/NICU	Interviews & focus groups	EoL in PICU	-Nurses role to prepare families for death -They feel that they know families best and use this rapport to support families -Death part of job, -Colleagues identified as a source of support to cope with death
Bloomer *et al*. (2016)	Nurse	Australia	Intensive & Critical Care Nursing	To explore nurses' experiences of caring for children at end of life	NICU and PICU nurses (n=13) Multiple PICU/NICU	Interviews & focus groups	EoL in PICU	-Role change to focus on families as death approaches -Create opportunities to let family be with their child and create memories
Bower *et al*. (2018)	Nurse	UK	Intensive and Critical Care Nursing	To explore nurses' views on interruption during medication administration	PICU nurses (n=10) Single PICU	Interviews & observation	Healthcare delivery	-Nurses felt a need to respond to interruptions -Multi-tasking while doing meds including observing the patient -Increased focus when medication was unfamiliar
Buckley *et al*. (2022)	Nurse	Canada	Frontiers in Pediatrics	To explore paediatric nurses' perspectives on their work environment, work attitudes, and experience of burnout	NICU & PICU Nurses (n=9) PICU/NICU	Interviews	Nursing as a healthcare professional	-Burnout is complex, difficult to self-identify but regularly occurs in nurses. -Burnout also impacts ability to find meaning in work. -Variety of work, acuity of care and team help reduce burnout -Felt that their role differs to other nurses around hospital therefore need different support.
Burton *et*	Nurse	Ca	Dimension	To better understand	NICU & PICU	Focus	Nurse as	-Nurses concerned with quality

***al*. (2020)**		na da	s of Critical Care Nursing	PICU & NICU nurses understanding and experience of moral distress	Nurses (n=57) Multiple PICU/NICU	groups	a healthcare professional	of life of patients and families -Concerns that families don't have adequate information due to communication issues -Nurses input not always valued can lead to moral distress -More moral distress when nurses do not agree with care plans -Some nurses had to leave due to clinical care
Butler *et al*. (2017)	Nurse	Au str alia	Nursing in Critical Care	To explore nurses' perceptions of working with families in the PICU	PICU nurses (n=5) Single PICU	Interviews	Family and patients in PICU	-Role as gatekeeper, not necessarily negative as it supports family's involvement in care provision -Difference caring for chronic vs acute patients -Controlled delivery of information based on perceived ability of families to cope -Act as channel between medical and families for communication -Continuity of care important but variety valued more by nurses
Carnevale et al. (2011)	Nurse	Ital y	Journal of Child Health Care	To understand decision-making around life sustaining treatment in PICU in Italy	PICU Nurses (n=26), parents & MDT Single PICU	Focus groups	EoL in PICU	-Nurses felt excluded from treatment decision-making -Nurses described the important contributions that they could make, given their relationships with parents. -Decisions and care provision contribute to moral distress

Carnevale *et al*. (2012)	Nurse	France & Canada	Journal of Child Health Care	To understand decision-making around life sustaining treatment in PICU in France and Canada	PICU Nurses (n= 24) & Medical team Multiple PICUs	Focus groups	EoL in PICU	-Nurses have in-between role when communicating -Frequently absent from meetings and commonly silent even when present -Often raise life-limiting therapy before medical team
Coats *et al*. (2018)	Nurse	US	American Journal of Critical Care	To explore nurses' perspectives on providing FCC in PICU	NICU & PICU Nurses (n=10) PICU/NICU	Interviews	Family and patient in PICU	-Family presence allows relationship building and nurses give parents jobs to be involved in care -Challenging when parents distract from care provision -Can be stressful having families present -Single rooms better for families but can be isolating for nurses
Craske *et al*. (2017)	Nurse	UK	Journal of Advanced Nursing	To explore nurses' decision-making around sedation withdrawal	PICU Nurses (n=12) Single PICU	Interviews	Healthcare delivery	-Caring for children on consecutive days enhances assessment -Use parents to support assessment to help identify normal behaviour for that child -Sedation weaning score does not support complex thinking involved in decision-making related to weaning
de Weerd *et al*. (2015)	Medical	Netherlands	European Journal of Pediatrics	To explore suffering in children while in PICU	PICU nurses (n=29), parents & MDT Single PICU	Interviews	Healthcare delivery	-Nurses were focused on the signs that caused discomfort and on the treatment of this discomfort -Focused on short-term perspective on suffering

Deja *et al*. (2021)	Researcher	UK	Pilot and Feasibility Studies	To explore parent and practitioner views on the acceptability of the proposed GASTRIC trial	PICU nurses (n=31), parents & MDT Single PICU	Interviews & focus groups	Healthcare delivery	-Nurses concerned over potential change in practice even though limited evidence to support it -Focus in PICU on doing things -Different views from some junior nurses related to trial acceptability
Denis-Larocque *et al.* (2017)	Nurse	Canada	Intensive & Critical Care Nursing	To explore nurses' perceptions of caring for parents of children with chronic medical complexity in the PICU	PICU nurses (n=10) Single PICU	Interviews	Family and patient in PICU	-Challenges due to parent as expert -Need to negotiate care with parents -Takes time to establish relationships
Dopson & Long-Sutehall. (2019)	Nurse	UK	Intensive & Critical Care Nursing	To explore PICU nurses' knowledge, attitudes, and feelings when donation after circulatory death is an option at end of life	PICU Nurses (n=8) Single PICU	Interviews & focus groups	EoL in PICU	-Limited education provided on donation -Nurses may be best placed to have these conversations as they know the patients best but reluctant to do so
Felipin *et al*. (2018)	Nurse	Brazil	Ciencia, Cuidado e Saude	To explore the meaning of family Centered Care	PICU and NICU nurses (n=19) PICU/NICU	Interviews	Families and patients in PICU	-Family extension of patient, aim to involve them in patient care -Believe parents help children recover -Parents gradually learn to provide care to their child in PICU
Foglia *et al*. (2010)	Nurse	US	Critical Care Nursing Quarterly	To explore factors that influence PICU nurses to leave their jobs	PICU Nurses (n=10) Single PICU	Interviews	Nurse as a healthcare professional	-Nurses describe the challenges of caring for sick children as a positive -Insufficient resources and support are stressors -Unrelieved stress as major reason leave job

Frechette *et al*. (2020a)	Nurse	Canada	Nursing in Critical Care	To examine PICU nurses' lived experience of caring for families following a major hospital transformation project.	PICU Nurses (n=15) Single PICU	Interviews & observation	Families and patients in PICU	-Gatekeeping occurs when nurse enforce rules and dictate parental role in care -Value an environment that offers personalised care -Often focused on the child rather than the family
Frechette *et al*. (2020b)	Nurse	Canada	Journal of Nursing Management	To explore nurses' professional identity following a redesign	PICU Nurses (n=15) Single PICU	Interviews & observation	Nurse a healthcare professional	-Reluctance to care for chronic long-term patients due to moral distress and pull from acute patients -Can be challenging to adjust to different care needs for chronic patients eg. Less monitoring -Can result in increased patient load when less acute which is challenging in single rooms
Gagnon & Kunyk (2022)	Nurse	Canada	Nursing Inquiry	To explore the moral distress experiences of PICU nurses caring for child patients who are dying	PICU Nurses (n=7) Multiple PICUs	Interviews	EoL in PICU	-Desire to give children dignified death that was peaceful -Burden of knowledge as an insider but not able to share with families can cause moral distress -Limited ability to be heard in decision-making -Use of language to communicate nurses' perspective -Nurse can experience moral distress when dignity not prioritised
Geoghegan	Resear	UK	Pediatric	To explore the	NICU & PICU	Interview	Families	-Significant impact of caring for

***et al*. (2016)**	cher		Critical Care Medicine	challenges of caring for long-stay patients in the PICU	Nurses (n=7) & MDT Single PICU	s	and patients in PICU	long-stay patients (LSP)- moral distress and low morale -Desire for variety of patients, particularly acute patients -Patients with no long-term plan most challenging
Gonzalez-Gil *et al*. (2021)	Nurse	Spain	Enfermeria Intensiva	To explore nurses' experience related to promoting the visits of siblings to PICU	PICU nurses (n=12) Single PICU	Interviews	Families and patients in PICU	-Emerging demand for sibling visits but no policy -Decisions not documented making consistency difficult -Overall nurses support visits but need to prepare environment to minimise distress
Greenway *et al*. (2019)	Medical	US	Pediatric critical care medicine	To explore barriers to communication in PICU	PICU nurses (n=3), parents & MDT Single PICU	Interviews	Families and patients in PICU	-Breakdown in communication when deviation from plan -Difference in findings from families, limited presentation of voice of nurse.
Henao-Castano & Quinonez-Mora (2019)	Nurse	Colombia	Enferm Intensiva	To explore nurses' coping with death in PICU	PICU nurses (n=10) Single PICU	Interviews	EoL in PICU	-Value of good communication -Focus on care provision at end of life and meaning from work
Ji *et al*. (2022)	Nurse	China	Journal of Nursing Management.	To explore ward and PICU nurses experiences of transferring patients out of PICU	Ward and PICU nurses (n= 14) Single PICU	Focus groups	Healthcare delivery	-Different priorities between ward and PICU nurses -Request for written handover to improve communication
Kahveci *et al*. (2014)	Medical	Turkey	Indian journal of pediatrics	To understand how decisions are made in PICU settings where critically ill children require life-support	PICU nurses (n=9), parents & MDT	Interviews	EoL in PICU	- Should be physician's responsibility to make the decisions in medically critical situations. - Nurses seemed to have more

				decision	Single PICU			understanding of the parents' feelings, compared to the doctors. -Decision-making gets easier with more experience in PICU
LaFond *et al*. (2015)	Nurse	US	Journal of Pediatric Nursing	To explore factors nurses, consider when assessing pain and selecting interventions in PICU	PICU nurses (n=40) Single PICU	Interviews & vignette questionnaires	Healthcare deliv	-PICU nurses used their own assessment over patient reported pain scores
LaFond *et al*. (2016)	Nurse	US	Journal of Pediatric Nursing	To describe PICU nurses' beliefs regarding the assessment and management of children's pain.	PICU nurses (n=40) Single PICU	Interviews & vignette questionnaire	Healthcare deliv	-Nurses use behaviour to describe pain over pain scores -Each patient unique making self-report difficult to rely on -Use experience to guide assessment
Lima *et al*. (2018)	Psychologist	Portugal	Nursing in critical care	To describe PICU nurses experiences with the sudden death of children/adolescents	NICU & PICU (n=36) Nurses Multiple PICU/NICU	Interviews & questionnaire	EoL in PICU	-Sudden death of patients resulted in significant impact on nurses -Experience helped with coping -Limited training and local support for this situation
Mahon (2014)	Nurse	Canada	Intensive and Critical Care Nursing	To explore PICU nurses job satisfaction through an ethnographic view of PICU	PICU Nurses (n=31) Single PICU	Interviews & observation	Nursing as a healthcare professional	-Change in way nurses spoke and communicate with experience -Value on experience and education -Lack of respect and power imbalance contributes to staff leaving -Value in provision of 'good death' doesn't contribute to intent to leave
Mattsson *et al*. (2011)	Nurse	Swed	Journal of Child	To explore nurses' clinical experiences of	PICU Nurses (n=17)	Interviews	Healthcare deliver	-Assessment on patient presentation

		en	Health Care	pain in non-verbal children in the PICU	Single PICU			-Use of experience to measure pain -Need to know patient baseline
Mattsson *et al*. (2022)	Nurse	Sweeden	SAGE Open Nursing	To explore nurses' challenges caring for children with substance withdrawal in the PICU	PICU nurses (n=5) Single PICU	Interviews	Healthcare delivery	-Focus on weaning to child's need not to desire to discharge from PICU -Need for correct language to communicate assessment based on experience
Medeiros *et al*. (2022)	Nurse	Brazil	Revista Brasileira de Enfermagem	To explore staff perceptions of their relationship with families of children during palliative care in PICU	NICU & PICU nurses and nurse technicians* (n=17) PICU/NICU	Interviews	EoL PICU	-Staff impacted by family acceptance of death -Influenced by communication of medical prognosis and false hope -Focus on care needs of child including keeping them pain free and family needs
Mesukko *et al*. (2020)	Nurse	Thailand	Pacific Rim International Journal of Nursing Research	To explore perspective of palliative care in PICU	PICU nurses (n=41) & medical team Multiple PICU/NICU	Interviews & focus groups	EoL PICU	-Communication essential for good pal care -Nurses should be at all planning meetings -Need for continuity of care at EoL -Nurses led symptom management related to EoL
Meyer (2014)	Nurse	US	Journal of Pediatric Nursing	To explore nurses' experiences caring for dying children	PICU Nurses (n=10) Single PICU	Interviews	EoL in PICU	-Difference in caring for children who are expected to die versus those who die unexpectedly in the same shift -When nurses realise approach of death, anxiety occurs until family updated -Step back emotionally from situation -Nurses provide care physically

								and medically and focus on creating order in the chaos
Meyer *et al*. (2012)	Nurse	US	Pediatric Critical Care Medicine	To explore practitioners' response to parents asking, 'what would you do if this is your child?' during simulation in PICU	PICU nurses (n=13) & MDT Single PICU	Simulation & interviews	EoL in PICU	-Focus on providing clinical information -Varied responses from practitioners including sharing personal information -Nurses focus on offering support
Michelson *et al*. (2011)	Medical	US	Pediatric Critical Care Medicine	To explore the processes used in EoL decision-making and the roles in family conferences (FC)	PICU nurses (n=23), parents & MDT Single PICU	Interviews & focus groups	EoL in PICU	-FC used to coordinate care and for communication -Nurses act as advocates -Nurses often asked questions after meeting even when not there -Nurses often absent due to competing demands
Michelson and Patel *et al*. (2013)	Medical	US	Pediatric Critical Care Medicine	To explore roles at end-of-life care	PICU nurses (n=23), parents & MDT Single PICU	Interviews & focus groups	EoL in PICU	-Nurses often act as family supporter and advocate -Information mainly given by medical team -Nurses often play role of secondary decision maker by censoring information given to families
Mitchell & Dale (2015)	Medical	UK	Palliative Medicine	To explore views regarding advance care planning (ACP) in pal care in PICU	PICU nurses (n=6) & medical team Single PICU	Interviews	EoL in PICU	-Failure to recognise approach of death stops ACP in practice -Nurses often recognise approach of EoL first -Considered good idea but needs MDT involvement -Moral distress when not acting in best interest of patient
Nilson *et al*. (2022)	Nurse	Brazil	Inquiry	To explore nurses' experience of the	PICU Nurses (n=25)	Interviews	EoL in PICU	-Research allowed nurses an opportunity to discuss this

				decision-making process related to therapeutic support limitation in PICU	Multiple PICUs			issue where they normally don't have voice -Predominantly mediator in decision-making -Feelings of frustration from exclusion
Park & Oh (2022)	Nurse	Korea	Child Health Nursing Research	To explore nurses and mothers' perceptions of partnership in PICU	PICU nurses (n=12) & Parents Single PICU	Interviews	Family and patient in PICU	-Differing views on partnership, nurses believe unequal due to knowledge imbalance -Focus on clinical care, reluctance to deliver information
Poompan *et al*. (2020)	Nurse	Thailand	Pacific Rim International Journal of Nursing Research	To explore experiences of EoL care in a Thai PICU	PICU nurses (n=24) & Parents Single PICU	Interviews & observation	EoL in PICU	-Nurses had to wait for medical team to redirect care before providing EoL care -Once change to comfort nurses lead care and support parents to make decisions and provide care -Nurses coordinate communication
Soares *et al*. (2020)	Nurse	Brazil	Revista Brasileira de Enfermagem	To explore nurses' perceptions of comfort in PICU	PICU nurses (n=40) and nurse technicians* Single PICU	Interviews	Healthcare delivery	-Nurses aim to promote comfort -Includes environmental for example noise and care specific including pain interventions
Schults *et al*. (2019)	Nurse	Australia	Australian Critical Care	To explore nursing practice of suctioning in PICU	PICU nurses (n=12) Single PICU	Interviews	Healthcare delivery	-Nurses use experience to decide suctioning practice -Aware of lack of research- they rely on own practice
Stayer & Lockhart (2020)	Nurse	US	American Journal of Critical	To explore PICU nurses' ability to cope with death	PICU nurses (n=12)	Interviews	EoL in PICU	-Death part of the job but its emotionally demanding -Focus on providing peaceful

			Care		Single PICU			end of children -Very hard when hope taken away but harder when reluctance to talk about death by medical team
van den Bos-Boon *et al*. (2021)	Nurse	Netherlands	Journal of Pediatric Nursing	To explore the effectiveness of sim training in resus skills	PICU nurses (n=19) Single PICU	Interviews & simulation observation	Nurse as a healthcare professional	-Sim training increased nurses' confidence in resus skills -Nurses had limited recognition of improvement of leadership communication during sim (traditionally medical led)
Vance *et al*. (2020)	Nurse	US	Advances in Neonatal Care	To explore perspectives in facilitating FCC	NICU & PICU Nurses (n=10) & Medical PICU/NICU	Interviews	Family and patients in PICU	-FCC nurse dependent -To promote FCC, they focused on communication to get everyone on same page -Decision-making happens ongoing not at a point in time -Unit design impacts FCC
Walter *et al*. (2019)	Medical	US	Journal of Pain and Symptom Management	To assess teamwork and communication with parents during family meetings.	PICU nurses (n=11) & medical Single PICU	Observation & Survey	Families and patients in PICU	-Nurses' contribution focused on providing medical information related to care at the bedside -They offered support and clarified elements for families
Watson & October (2016)	Nurse	US	American Journal of Critical Care	To explore clinical nurse participation in family meetings	PICU nurses (47 survey & nurses in meetings) Single PICU	Observation & survey	Families and patients in PICU	-A clinical nurse attended 20 (50%) of the family conferences that were audio-recorded but only made contribution in 25% of them. -Unable to attend due to clinical demands -Being present allows them to be present to hear news firsthand -nurses who did not speak said

								they had wanted to speak, and some of the reasons provided were that they were "uncomfortable speaking," "were not asked"
Wei *et al*. (2020)	Nurse	US	Critical Care Nurse	To explore self-care to prevent burnout for staff in PICU	PICU nurses (n=13) & Medical Single PICU	Interviews	Nurse as a healthcare professional	-Finding meaning in work kept staff motivated -Support from colleagues important
Zheng *et al*. (2018)	Researcher	Canada	Pediatric Critical Care Medicine	To explore impressions of early mobilization of critically ill children	PICU nurses (n=10), parents & MDT Single PICU	Interviews	Healthcare delivery	-Early mobility important but not a priority -Felt like they had responsibility, but it increased workload