Family Experience and PICU Death: A Meta-Synthesis

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BACKGROUND AND OBJECTIVES: The PICU is the most common site for inpatient pediatric deaths worldwide. The impact of this clinical context on family experiences of their child’s death is unclear. The objective of the study was to review and synthesize the best available evidence exploring the family experience of the death of their child in the PICU.

METHODS: Studies were retrieved from CINAHL Plus, OVID Medline, Scopus, PsycINFO, and Embase. Gray literature was retrieved from greylit.com, opengrey.edu, Trove, Worldcat, and Google scholar. Study selection was undertaken by 4 reviewers by using a multistep screening process, based on a previously developed protocol (International Prospective Register of Systematic Reviews 2015:CRD42015017463). Data was extracted as first-order constructs (direct quotes) or second-order constructs (author interpretations) onto a predeveloped extraction tool. Data were analyzed by thematic synthesis.

RESULTS: One main theme and 3 subthemes emerged. “Reclaiming parenthood” encompasses the ways in which the parental role is threatened when a child is dying in the PICU, with the subthemes “Being a parent in the PICU,” “Being supported,” and “Parenting after death” elucidating the ways parents work to reclaim this role. The review is limited by a language bias, and by the limitations of the primary studies.

CONCLUSIONS: When a child dies in a PICU, many aspects of the technology, environment, and staff actions present a threat to the parental role both during and after the child’s death. Reclaiming this role requires support from health care providers and the wider community.

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Ms Butler conceptualized and designed the study, completed search and full text sourcing, participated in the review, data extraction, and data analysis process, and drafted the initial manuscript; Drs Hall, Willetts, and Copnell conceptualized and designed the study, and participated in the review, data extraction, and data analysis process; and all authors reviewed and revised the manuscript and approved the final manuscript as submitted.

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International data suggests that 2% to 10% of children admitted to a PICU die during their stay\(^1\)–\(^6\) with these deaths accounting for more than 80% of all inpatient pediatric deaths.\(^7\)\(^,\)\(^8\) Research from Australia,\(^4\)\(^,\)\(^5\)\(^,\)\(^9\) the United States,\(^10\)\(^,\)\(^11\) and the United Kingdom\(^1\) has found that children most frequently die as a result of withdrawal of life support, whereas studies from Brazil,\(^3\) France, and Eastern and Central Europe\(^2\) identify that most children die in PICUs as a result of failed cardiopulmonary resuscitation. Some have argued that this can be attributed largely to cultural differences related to end-of-life care practices and the social acceptance of the death of a child.\(^2\)\(^,\)\(^12\)\(^,\)\(^13\)

Traditionally, critical care environments have had a high focus on technologically driven care aimed toward sustaining life, where death may be viewed as a failure of skill and technology.\(^14\)\(^,\)\(^15\) Although the implementation of palliative care into PICU settings is increasing, some staff are unprepared for the impending death of a child, and possibly lack the skills required to care for families during this time.\(^8\) This may have devastating consequences for the family’s experience, leaving a lasting impact on their memories of the child’s final moments.\(^16\)\(^,\)\(^17\)

A literature review that examined parents’ perceptions of end-of-life care in the PICU\(^10\) highlighted many important aspects of end-of-life care for families in this environment. Significant factors included clear and honest communication and decision-making, maintaining the parent-child relationship, and the need for bereavement support and follow-up care.\(^18\) However, this review focused solely on parental perceptions of end-of-life care, rather than including the experiences and needs of siblings or other family members during this time. There is an urgent need to systematically examine studies that explore the whole family experiences and needs, to inform the development of effective, holistic, and parent-driven guidelines for end-of-life and bereavement follow-up care in a PICU environment.

**AIM**

The objective of this systematic review was to review, critically appraise, and synthesize the best available evidence exploring experiences of the death of a child in the PICU, from the perspective of the child’s family.

**METHODS**

This meta-synthesis was conducted according to a protocol developed by the authors before undertaking the review. Details of the protocol for this systematic review were registered on the International Prospective Register of Systematic Reviews (CRD42015017463). This review is reported in accordance with the Preferred Reporting Items for Systematic reviews and Meta-Analyses guidelines (where appropriate for qualitative reviews) and the enhancing transparency in reporting the synthesis of qualitative research statement.\(^19\)

**Search Strategy**

Initially, a search of the 5 databases was undertaken by the first author, in consultation with an expert librarian: CINAHL Plus, OVID Medline, Scopus, PsycINFO, and Embase. Search terms were developed using a modified population, intervention, comparison, and outcomes tool (Table 1). Additionally, reference lists were hand searched for potential articles, and gray literature was obtained from Trove.nla.gov.au, Worldcat.org, open gray.edu, greylit.com and Google Scholar. Duplicates were removed before screening.

**Study Selection Process**

Citations underwent a 2-stage screening process to assess for relevance: title and abstract, and full text. Study selection was undertaken by a main reviewer (AB), with 3 additional reviewers providing secondary independent review of all citations, based on inclusion criteria in Fig 1. Disagreements between reviewers were discussed, and resolved with a third reviewer where required. A flow chart of the search strategy can be seen in Fig 2.

**Critical Appraisal**

Critical appraisal was undertaken using the Critical Appraisal Skills Program (CASP)\(^20\) checklist to determine the quality of the study, and assess its appropriateness for inclusion into the review. The CASP tool is a 10-question checklist, specific to qualitative studies, used to assess methodological rigor and determine the trustworthiness of the findings. The appraisal process was undertaken by all 4 reviewers as outlined previously, and in accordance with the reviewer guidelines outlined in the
review protocol. A breakdown of the CASP scores for each included study, and an outline of the scoring system, can be seen in Table 2.

Three articles21–23 were written directly by parents as a narrative account of their time in the PICU. As these articles were not studies, but rather primary raw data from the parents themselves, they were not appraised by using the CASP checklist, but were still included in the review, and treated as highly valuable data based on “expert” opinion.
numbers of deceased children) in 21 PICUs (Italy ×1, Brazil ×2, United States ×18). An overview of these studies is presented in Table 3.

Findings
One main theme, Reclaiming Parenthood, was developed from the data, which comprised 3 smaller subthemes: Being a Parent in PICU, Being Supported, and Parenting After Death. A table outlining the theme structure and further illustrative quotes can be seen in Supplemental Table 4.

Reclaiming Parenthood
The central theme, Reclaiming Parenthood, describes the challenges parents faced in maintaining their role when their child was dying in the PICU. The threat to the parental role arose both through the environment and equipment needed to care for the child, and through the actions of staff, which could also leave parents feeling disempowered. Parents often used phrases that were suggestive of disempowerment, such as “they wouldn’t allow me to stay in the room,”25 “I was told not to touch her,”26 and “it would be nice to have a little more say in when things were done.”27 This suggests a lack of control on the part of the parent over their ability to be present with and provide care for their child. The perceived power staff had over the parents’ ability to undertake their expected role was manifested in many other ways. Participants felt excluded from decisions about their child, noting that “they explained everything and I was a listener, because I did not decide anything,”28 or feeling that the use of medical jargon left them unable to understand and therefore unable to participate in discussions. Parents also recounted times when they were asked to leave the room, such as during emergencies or procedures, and noted that sometimes staff “came in during the day...then they walked out. And, kind of ignored us a little bit.”29 Additionally, the very equipment and technology used to care for their child also alienated the parents, hindering their ability to touch or interact with their child. The child also was removed from the parents in a more abstract way: sedative medications led to the child being absent, and staff control over parental ability to touch or care for their child led to a sense that their child belonged to the PICU staff rather than them. Consequently, parents worked to reclaim their parenthood; the ways in which they did this are explored in the following subthemes.

Being a Parent in PICU
This subtheme encompasses the activities in which parents engaged to reclaim and redefine their role with their dying child. Being a Parent in PICU includes the concepts of “forging a parental role,” “keeping informed,” “preserving the child’s personhood,” and “creating a family environment.”

Forging a parental role was a key aspect for parents. They wanted to be present with their child through the dying process, noting it “was most helpful to be with her through the discontinuation of life support.”30 Although some parents valued being able to participate in their child’s care, most felt that the main source of intimacy they could achieve with their child was through touch. Being able to touch their child or “…hold her as long as we wanted. We were able to rock her in our arms and feel her little body”31 was extremely important to parents, both before and after their child had died. Sufficient time to say goodbye was also vital, with some parents noting they were rushed or hurried after their child’s death.

Keeping informed was also an important aspect of creating and maintaining a parental role. Parents often desired much more input into decisions than they were offered, noting that “as a mother, I thought I would participate. I think any parent, any family there; I think any parent, I think I’d like to participate at the time of their decision.”32 To make decisions for their child, parents needed complete, honest, and accurate information, especially about prognosis, which was often withheld. To overcome this barrier, parents learned other ways to obtain information: they exerted significant effort trying to obtain information from staff through participation in medical ward rounds, and learning to “figure out ways to get our own second opinions.”31

Preserving the child’s personhood also was important to many parents, who needed staff to recognize the child as an individual. Parents reported becoming distressed when the child was not treated as an
<table>
<thead>
<tr>
<th>Author (Year)</th>
<th>Country</th>
<th>Aim</th>
<th>Methodology</th>
<th>Sample</th>
<th>Data Collection</th>
<th>Main Findings</th>
<th>Strengths</th>
<th>Weaknesses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abib el Halal et al (2013)28</td>
<td>Brazil</td>
<td>To explore parents’ perspectives of the quality of care offered in their child’s last days of life in the PICU</td>
<td>Qualitative exploratory design</td>
<td>15 parents of 9 children: 9 women and 6 men</td>
<td>Semistructured interviews (face to face)</td>
<td>3 reported: Quality of communication in PICU, Parent’s participation in decision making, The moments surrounding death</td>
<td>Good discussion of ethical aspects of study</td>
<td>2 small hospitals from the same region, Limited discussion of impact of researcher, No discussion of who did data analysis, Small sample</td>
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<tr>
<td>Dokken (2006)21</td>
<td>—</td>
<td>To examine parents’ perspectives of good and poor communication with medical staff who cared for child before their death in the PICU</td>
<td>Expert opinion</td>
<td>51 interviews with bereaved parents</td>
<td>Semistructured interviews (phone)</td>
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<tr>
<td>Gordon et al (2009)29 USA</td>
<td>—</td>
<td>To explore parental experiences of end-of-life care in the PICU</td>
<td>Hermeneutic phenomenology</td>
<td>8 interviews with 12 participants: 4 couples, 3 mothers, 1 father</td>
<td>Semistructured interviews (face to face)</td>
<td>Loss of parental control</td>
<td>Good use of multiple investigators for data analysis</td>
<td>Small sample</td>
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<tr>
<td>Lamiani et al (2013)26</td>
<td>Italy</td>
<td>To explore parental experiences of end-of-life care in the PICU</td>
<td>Expert opinion</td>
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<td>Author (Year)</td>
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<td>McGraw et al (2012)</td>
<td>USA</td>
<td>To explore how parents whose child died in the PICU understood their roles, and define the most essential activities and responsibilities at the time surrounding the child's death.</td>
<td>Qualitative data from a mixed methods study</td>
<td>18 parents: 17 mothers 1 father</td>
<td>Semistructured interviews (phone)</td>
<td>Providing love, comfort, and care</td>
<td>Multiple coders for data analysis</td>
<td>Predominantly female sample</td>
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<tr>
<td>Meert et al (2005)</td>
<td>USA</td>
<td>To investigate the spiritual needs of bereaved parents</td>
<td>Qualitative methodology (not specified)</td>
<td>33 parents: 20 mothers 12 fathers 1 grandmother (guardian)</td>
<td>Semistructured interviews (face to face)</td>
<td>Connecting with the child</td>
<td>Good justification for use of qualitative methods</td>
<td>Single site study</td>
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<tr>
<td>Meert et al (2008)</td>
<td>USA</td>
<td>To explore parents' environmental needs during their child's death in the PICU</td>
<td>Phenomenology</td>
<td>33 parents: 20 mothers 12 fathers 1 other female relative</td>
<td>Semistructured interviews (face to face)</td>
<td>Places remembered</td>
<td>Excellent discussion of study setting</td>
<td>Single site</td>
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**Main Findings:**
- Providing love, comfort, and care
- Creating security and privacy for the family
- Exercising responsibility for what happens to one's child
- Connecting with the child
- Truth
- Compassion
- Prayer, ritual, and sacred text
- Connection with others
- Bereavement support
- Gratitude
- Meaning and purpose
- Trust
- Anger and blame
- Dignity
- Excellent discussion of study setting
- Use of 2 independent data coders
- Good mix of male and female participants.
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<thead>
<tr>
<th>Author (Year)</th>
<th>Aim</th>
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<th>Strengths</th>
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<tr>
<td>Meert et al. (2008)</td>
<td>To describe parents' perceptions of their conversations with physicians regarding their child's illness and death in the PICU</td>
<td>Secondary analysis of previous qualitative research (not specified)</td>
<td>34 USA</td>
<td>56 parents: Semistructured interviews (phone)</td>
<td>Parental perceptions of physician conversations:</td>
<td>Excellent discussion of recruitment issues</td>
<td>No discussion of impact of researcher on the study</td>
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<td>Availability</td>
<td>Strong discussion of data collection and analysis considerations</td>
<td>Mainly female sample</td>
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<td>Honesty and comprehensiveness</td>
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<td>Withholding information and providing false hope</td>
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<td>Vocabulary and pace</td>
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<td>Body language</td>
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<td>Meert et al. (2009)</td>
<td>To gain a deeper understanding of parents' needs around the time of their child's death in the PICU</td>
<td>3-phase, sequential, qualitative study (not specified)</td>
<td>32 USA</td>
<td>Phase 1 (interviews): Semistructured interviews (face to face)</td>
<td>4 main themes found:</td>
<td>Excellent triangulation of data</td>
<td>No discussion of the impact of the researcher on data collection or analysis</td>
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<td>21 mothers</td>
<td>Who I am</td>
<td>Good description of recruitment and data collection</td>
<td>No discussion on psychological support provided to the participants</td>
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<td>12 fathers</td>
<td>While my child was dying</td>
<td>Good discussion of sample characteristics</td>
<td>Single-site study</td>
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<td>Phase 2 (focus groups): 9 mothers</td>
<td>My child's death context</td>
<td>Good use of member checking and multiple investigators</td>
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<td>4 fathers</td>
<td>My bereavement journey</td>
<td>Discussion provided of how researchers responded to events during the study</td>
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<td>Merk and Merk (2013)</td>
<td>To identify parents' priorities and recommendations for improving end-of-life care in the PICU</td>
<td>Expert opinion</td>
<td>23 USA</td>
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<td>Meyer et al. (2006)</td>
<td>To identify parents' priorities and recommendations for improving end-of-life care in the PICU</td>
<td>Retrospective questionnaires (qualitative data)</td>
<td>30 USA</td>
<td>56 completed questionnaires: 36 mothers</td>
<td>Key parental recommendations and priorities:</td>
<td>Good representation of male caregiver opinions</td>
<td>No discussion of sampling technique</td>
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<td>20 fathers</td>
<td>Honest and complete information</td>
<td>No discussion of questionnaire development</td>
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<td>Ready access to staff</td>
<td>No discussion of the impact of the researcher on tool development or data analysis</td>
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<td>Communication and care coordination</td>
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<td>Emotional expression and support by staff</td>
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<td>Preservation of the integrity of the parent-child relationship</td>
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<td>Faith</td>
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<td>Michelson et al (2013) USA</td>
<td>To describe issues important in end-of-life care decision-making for parents in the PICU</td>
<td>Retrospective qualitative study</td>
<td>18 interviews: Semistructured interviews (face to face)</td>
<td>Roles and responsibilities of staff: Family supporter, Parent advocate, Information giver</td>
<td>Good discussion of the impact of the researcher on the research, including modification of the research process</td>
<td>Single site</td>
<td></td>
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<tr>
<td>Robinson et al (2006) USA</td>
<td>To examine the nature and role of spirituality and religion at the end of life</td>
<td>Retrospective questionnaire (from a larger study)</td>
<td>56 completed questionnaires: 36 mothers, 20 fathers</td>
<td>Parental perspectives questionnaire, Explicitly spiritual themes: Prayer, Faith</td>
<td>Multisite study, Good representation of male viewpoints</td>
<td>No discussion of recruitment</td>
<td></td>
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<tr>
<td>Yorke (2011) USA</td>
<td>To explore parents' memories of having a child die in the PICU</td>
<td>Mixed-methods study (not specified)</td>
<td>15 interviews with 23 parents</td>
<td>Semistructured interviews (phone), Findings groups into themes: What do families remember about having a child die in the PICU? What recommendations do families have? What do parents consider essential to a good death in PICU? Other information shared</td>
<td>Good discussion of recruitment techniques</td>
<td>Small sample, Very limited sample demographics provided</td>
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individual person by the staff. They highly valued staff who took time to get to know their child and use their name, appreciating it when staff continued “checking his signs and taking care of him like he was still a person there.”

Finally, many parents spent time creating a family environment in the PICU. They often noted the PICU was crowded, noisy, and bright, and “the nurse was always there watching... And there were other families there with their child. And they were all watching, realizing that this is a critical case. So I would say there wasn’t much privacy at that stage of the game....”

Parents wanted more control over visitors, lighting, temperature, and noise, and desired “designated areas where, not to die areas, but you know, if it gets serious, it should be quiet. It should be corded off” to increase privacy and allow for family visitation and intimacy during the child’s final days.

**Being Supported**

The second subtheme, Being Supported, focused on the physical, social and practical supports and resources parents needed to reclaim their parental role in the PICU. The subtheme includes the concepts of “Staff Support,” “Spiritual Support,” “Social Support,” and “Practical Support.”

The concept of Staff Support was prominent through the studies. Parents needed staff who were “gentle and empathetic to what we were going through,” who offered comfort, and who provided care toward the parents themselves. They needed the staff to be a “link between you and the unknown,” preparing them psychologically for what was happening and guiding them through the process. Parents also highly valued staff displays of emotion, finding it helpful when “the staff stood there with us and shared our grief...they communicated volumes with the simple act,” and noting that “it was very moving to see all these emotions [from staff] because they had watched her fight for days.”

When caring and compassionate aspects were missing, parents felt that “everybody just basically did their job and that was it.” Such staff were perceived to have a cold, matter-of-fact tone, or were noted to display inappropriate or insensitive comments to parents, which left parents feeling uncared for and creating long-lasting negative memories of their child’s final days.

Parents also had a strong need for Spiritual Support when their child was in the PICU. They valued the comfort, guidance, and support of religious leaders, both personal and those affiliated with the hospital. Parents gained strength and comfort from reading religious texts, praying and being able to undertake spiritual rituals, and relied on these methods and their values to assist in end-of-life decision-making. Religious communities also were a source of significant comfort and support to parents, who valued knowing that the community was praying for their family.

Also valuable to parents was the Social Support they received from family and friends. It was important to parents that family and friends be present to support and care for them and their child, and “just to have everybody there, have everybody say that they felt our pain,” rather than having to manage grief alone. Support persons also were able to provide practical help to parents, bringing food, clothing, and an opportunity for respite away from the child’s bed. Parents also highly valued being able to “talk to parents who have children with the same problem and who lost their kids and stuff. ‘Cause talking to someone with the same problems, whose child dies with the same hypoplastic left heart as mine, exchanging stories and stuff was good,” as it helped them feel they were not alone in their experiences and grief.

Finally, parents needed Practical Supports to facilitate their parental role in PICU. They described the need for a multitude of places within the hospital to support them in their roles: they wanted space to accommodate family and friends, quiet spaces for time out and reflection, fresh air, and a place to sleep near the PICU. Parents also frequently mentioned the need for a space to have discussions about the child’s care and prognosis, but were inconsistent about where this should be: by the child’s bed, or in a conference room or office. In addition to physical places, parents needed resources to allow them to care for themselves. They wanted a comfortable chair to sit by their child, “a place to get a meal” or a drink close by, a place to shower and wash things, “a place to keep your personal belongings,” and access to phones and the Internet. Additionally, some parents mentioned the need for “help for my kids, the survivors, of course they were devastated,” and provision of child care facilities.

**Parenting After Death**

The subtheme Parenting After Death examines the ways in which parents attempt to reconstruct and maintain their parental role after their child has died. The theme encompasses the concepts of “Needing Follow-up,” “Remembering the Child,” and “Making Meaning.”

The concept of Needing Follow-up is central to this subtheme. Parents desired “a support system that follows up” from the hospital. They noted a lack of bereavement follow-up or ongoing support from the hospital after their child’s death, and recommended that there should be “a phone call, send out a package with all types of information especially about the grieving process.” Parents greatly appreciated when they received ongoing contact from staff through letters, cards, or funeral attendance, noting that “saying goodbye to [his] caregivers was an
added burden to that of grieving the loss of [the child],

Remembering the Child focuses on the ways that bereaved parents work to incorporate the memory of their deceased child into their lives. Mementos, or objects related to the child, were highly valued as a way to maintain a connection to the child. Parents also had a need to “say goodbye properly to the place where [the child] had died,”22 and valued hospital memorial services as a means of returning and honoring the child. Many parents remembered their child by talking about him or her, and valued these opportunities, as they assisted in the healing process and provided comfort.

Last, Making Meaning out of the child’s life and death was important for many parents. They used their experiences to help others who faced the death of a child, or consented to an autopsy in the hopes it would allow others to learn from their child’s death. Parents also searched for meaning in their child’s life as a source of comfort; they recalled the joy and good their child brought into others’ lives, and used this to show how their child’s life had meaning, even through illness and death.

**DISCUSSION**

This meta-synthesis examined parental experiences of the death of their child in the PICU. Our findings indicate that parents often feel disempowered by the PICU environment and the actions of the staff, and use a variety of strategies to reclaim their role.

Parental disempowerment and the threatened parental role emerged as a key finding in this review. This appears to arise both from the physical environment of the PICU, and from the actions of staff, whether intentional or not. Although this concept has been discussed in the broader PICU literature,37–40 it has not previously been identified as such in the literature surrounding end-of-life care in PICU. The finding suggests that, for parents, there is no discernible change in the way the parental role is facilitated during death and bereavement in the PICU. The review also highlighted the many ways parents worked to overcome their disempowerment and attempt to reclaim their parental role. This entailed engaging in activities that facilitated and encouraged typical parental responsibilities, such as involvement in caregiving, or seeking information about the child’s medical condition and input into decision-making. Individually, these actions have been identified as important dimensions of the parental role in the general PICU literature,34,41–43 but to our knowledge have not been collectively identified as an attempt to reclaim a threatened role with a dying child. It is possible that a modification of the PICU environment to facilitate the parental role and become more “family-centered” (such as family-led care or policy) would reduce or eliminate many of the aspects that disempower parents. Studies implementing and evaluating such changes would be worthwhile.

The review findings also highlighted the parents’ need for the child to be overtly acknowledged and treated as a person by the PICU staff. Parents may sometimes perceive that the staff do not recognize their child as a person, and instead see only the disease, especially if complex medical equipment is required. However, when staff touch or talk to the child, or use the child’s name, this perception may be overcome, with parents instead feeling that their child remains a person in the eyes of the staff. Although this concept is not new, this review demonstrates that the importance of maintaining the child’s personhood may be closely linked to the parents’ attempts to maintain their own role. Further study examining the relationship between the concepts of the child’s personhood and maintenance of the parental role in the hospital setting is warranted.

Our results show that PICU parents have complex needs that require support and care from multiple people. Of particular importance was the need for compassionate, caring, and empathetic health care providers. A recent review of parental experiences of health care provider actions when a child died found that insensitive, cold, or inappropriate actions from staff left parents with negative memories of their child’s death, leading to prolonged and increased emotional distress.44 Similar findings were uncovered in this review, which found that poor staff affect left parents feeling uncared for, and created lasting negative impressions of their child’s last days. Increased staff education and training on pediatric end-of-life and bereavement care may improve the care and support offered to dying children and their families, and should be routinely offered in all PICU settings.

Also highlighted is the continued importance of the parental role and connection to the child after the child’s death. Objects related to the child often provide comfort to the parents, who value keeping the last blanket or item of clothing used by the child. Studies show that most US hospitals offer memento-making activities to parents of dying children, most commonly hand/foot prints, locks of hair, and photos.45 Although these are valued by parents, our findings suggest that nontraditional objects, such as hospital gowns or identification bracelets, also may be desired, but are often refused. Further studies exploring which memento items are desired by parents may provide invaluable guidance to staff and may help to change hospital policy that prohibits the provision of nontraditional items.

Additionally, we found that although ongoing contact with hospital staff
was desired by many bereaved parents, it was often lacking. There is limited literature examining the extent of bereavement follow-up after death in PICU. What does exist identifies a haphazard approach, largely dependent on the preexisting relationships between staff and families, leaving parents feeling abandoned by hospital staff. Therefore, we recommend the implementation of an organized bereavement follow-up program in each PICU, to maintain support to families in the first months after their child’s death.

Finally, the review identified a need to make meaning of the child’s life and death, and identified helping others as a possible means to do so. Given that some parents discussed the benefits of talking to other bereaved parents, implementing a support group led by bereaved parents may provide a double benefit: it may facilitate the provision of support delivered by bereaved parents, and allow those parents to use their experiences to help others and give some meaning to their child’s death.

Limitations of the review include both limitations of the search strategy, and the limitations of the primary studies themselves. Although we made every effort to include gray literature, we were unable to obtain enough information from authors to facilitate inclusion of any unpublished studies into the review, leading to a potential selection and publication bias. Additionally, we were unable to obtain translated copies of several non–English-language publications, leading to a language bias. Most included studies were undertaken in the United States, and mainly examined the experiences of white parents, most commonly mothers. The extent to which these findings can be extrapolated to a more ethnically diverse population may be limited, and, as such, we recommend that future studies in the area focus on a more culturally diverse population. We also recommend that studies be conducted in locations outside of the United States, to explore the impacts that different models of care may have on the family experience. Overall, most studies had adequate inclusion of male participants, although 2 studies were dominated by female participants. Studies that specifically target fathers or male caregivers also are important in continuing to improve our understanding of their unique experiences, and should be a priority for future research. Importantly, the aim of this study was to explore the whole family experience; however, we were unable to identify any research that examined the experiences of siblings, grandparents, or extended family. Research including these populations is urgently needed, to ensure the delivery of holistic end-of-life care.

CONCLUSIONS

Although this review aimed to examine the whole family experiences of a child’s death in PICU, a lack of literature on wider family experiences meant that only those of parents could be included in the review. Highlighted was the disempowerment that parents often feel when their child dies in the PICU. The parental role is threatened by the environment and equipment, and by the actions of some PICU staff. Parents worked to reclaim their role by ensuring they were informed about their child’s care, being present and participating in caring for their child, maintaining the child’s personhood, and creating a family environment. They also worked toward maintaining their parental role after the death of their child through memory and meaning-making activities. However, these attempts to reclaim their role required support and resources from staff, friends and family, and spiritual leaders, which were not always willingly provided. Given that the PICU remains the most common location for pediatric inpatient deaths, it is imperative that staff work toward designing an environment and care delivery system that supports parents to maintain their parental role, to maintain the family unit, and deliver holistic, family-centered end-of-life care.

ABBREVIATION

CASP: Critical Appraisal Skills Program

REFERENCES


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