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Research paper

Welcoming expertise: Bereaved parents' perceptions of the parent–healthcare provider relationship when a critically ill child is admitted to the paediatric intensive care unit

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ABSTRACT

Background: Entering the paediatric intensive care unit with a critically ill child is a stressful experience for parents. In addition to fearing for their child's well-being, parents must navigate both a challenging environment and numerous new relationships with healthcare staff. How parents form relationships with staff and how they perceive both their own and the healthcare providers' roles in this early stage of their paediatric intensive care journey is currently unknown.
Purpose: This paper explores bereaved parents' perceptions of their role and their relationships with healthcare providers when their child is admitted to the intensive care unit, as part of a larger study exploring their experiences when their child dies in intensive care.
Methods: A constructivist grounded theory approach was utilised to recruit 26 bereaved parents from 4 Australian intensive care units. Parents participated in audio-recorded, semi-structured interviews lasting 90–150 min. All data were analysed using the constant comparative analysis processes, supported by theoretical memos.
Results: Upon admission, parents viewed healthcare providers as experts, both of their child's medical care and of the hospital system. This expertise was welcomed, with the parent–healthcare provider relationship developing around the child's need for medical care. Parents engaged in 2 key behaviours in their relationships with staff: prioritising survival, and learning 'the system'. Within each of these behaviours are several subcategories, including 'Stepping back', 'Accepting restrictions' and 'Deferring to medical advice'.
Conclusions: The relationships between parents and staff shift and change across the child's admission and subsequent death in the paediatric intensive care unit. However, upon admission, this relationship centres around the child's potential survival and their need for medical care, and the parent's recognition of the healthcare staff as experts of both the child's care and the hospital system.

1. Introduction

Although the vast majority of children admitted to the paediatric intensive care unit (PICU) are discharged home, approximately 2–10% of critically ill children around the world will die during their admission.[1–6] Bereaved parents' experiences of their child's death in PICU have been explored, with prior research focusing on their experiences in general,[7–13] or on their experiences of end-of-life communication,[14,15] the PICU environment,[16] their parental role,[17] their spirituality,[18,19] or of follow-up care.[10,20–22] However, parents' experiences of their child's death do not happen in isolation but instead occur as part of a broader hospital experience, beginning with admission to the PICU. Prior research with non-bereaved parents has demonstrated the difficulties parents may face as they enter the PICU with a critically ill child. The minutes and hours of initial admission are usually a flurry of activity, with

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emergency treatments, interventions and investigations undertaken. Parents often fear for their child's life and may be overwhelmed by the equipment and technology required for survival and by changes to the child's appearance.[23,24] The environment, described as being 'an alien world',[25] is unfamiliar and confusing, and is filled with a vast number of healthcare providers (HCPs) with whom parents must interact.[25,26]

Despite the difficulties that the PICU admission period can bring, very little is currently known about bereaved parents' experiences of this time, or of their perceptions of and interactions with the healthcare providers they encounter. While it is generally well accepted that most bereaved parents desire some level of involvement and partnership in care when they are aware their child is dying in the PICU,[13,17,27,28] it is possible that their needs and desires may have changed as they moved through the continuum of grief. It is unclear whether they also desire involvement in their child's care and partnership with healthcare staff in the first hours and days of their child's admission, when the possibility of survival remains. When these understandings are lacking, healthcare providers may make incorrect assumptions about the relationships that parents desire, with their subsequent behaviours potentially leaving lasting negative impressions on the parents' overall experiences.[29] To address these gaps in understanding, we explore bereaved parents' perceptions of their role and the relationships they form with healthcare providers during the initial PICU admission period.

2. Materials and methods

We utilised a constructivist grounded theory methodology to explore the experiences of bereaved parents when their child died in the PICU, with a focus on their interactions and relationships with HCPs from admission through to their bereavement journey.[30] This paper presents one aspect of the findings from this larger study. Grounded theory focuses on exploring human behaviour and interaction in social contexts, aiming to develop a theory to explain what is occurring in the data.[30] The constructivist school, led by Charmaz, asserts that knowledge and data are not 'discovered', but rather are jointly constructed by both the participants and the researcher(s).[30] In addition, constructivism also embraces the concept of multiple individual realities, influenced by history, personal experience, and socio-cultural environment.[30] For these reasons, constructivist grounded theory was particularly suited to the aims of our research.

After obtaining ethical approval, we employed purposive and theoretical sampling techniques to invite parents to participate in the study. Mailed letters, social workers, and bereavement support group advertisements were used to recruit bereaved parents from four Australian PICUs 6–48 months after their child had died. A more detailed discussion of our recruitment procedures is provided elsewhere.[31]

Written informed consent was provided by 18 mothers and 8 fathers, who participated in semi-structured audio-recorded interviews. These parents represented 18 children, who died from congenital heart disease (4), sudden unexplained death in infancy (3), other single organ dysfunction (2), multi-organ dysfunction (2), neurological injury (2), and 1 each of sepsis, metabolic disease, cardiac arrest, accident and anaphylaxis. To give context to the findings and the parents' experiences of the healthcare system, characteristics of participating parents have been provided in Table 1.

Interviews were based on an interview guide, with questions evolving over the course of the study to focus on developing concepts and categories, consistent with theoretical sampling techniques common to grounded theory.[30] During early interviews, parents were invited to share their PICU journey, beginning with asking them to explain their family and how they came to be in the PICU with their child. Later interviews explored developing concepts, such as the parents' experiences of their PICU admission up until the point where they learnt that their child would die. Most parents elected to be interviewed in their own homes, though a small number preferred phone interviews, with each interview lasting 90–150 min. All interviews were undertaken by the first author, a PICU nurse and qualitative researcher who had also undertaken a bereavement counselling course, and who had no prior relationship with any participant. Field notes were made of conversations that occurred after the recorder was stopped, with permission. Participants were followed up 1 week after their interviews to check on their welfare, with social workers available for psychological support if required.

Table 1
Characteristics of included families.

Characteristic	Parent(s)
Child's age	
• 0–1 year	Joshua and Evelyn; Emma; Abigail; Vicki and Nate; Layla; Sarah and Connor; Zoe and Charlie; Jessica; Jasmine
• 1–5 years	Lucy and Hudson; Alice; Imogen; Erin
• 5–12 years	–
• Teenager	Hannah and Daniel; Zara and Ryan; Eva; Isabelle; Piper and Edward
Illness type	
• Acute	Emma; Lucy and Hudson; Zara and Ryan; Eva; Isabelle; Alice; Imogen; Vicki and Nate; Sarah and Connor; Zoe and Charlie; Jasmine
• Chronic	Joshua and Evelyn; Hannah and Daniel; Abigail; Piper and Edward; Layla; Jessica; Erin
Prior hospital experience	
• NICU	Abigail; Imogen; Layla; Jessica; Erin
• Ward	Joshua and Evelyn; Piper and Edward
• Healthcare worker	Zara; Isabelle; Vicki
• None	Emma; Lucy and Hudson; Hannah and Daniel; Ryan; Eva; Alice; Nate; Sarah and Connor; Zoe and Charlie; Jasmine

All transcribed data were entered into NVivo 10, where open, focused and theoretical coding and the constant comparison method were used for data analysis by the first author, in collaboration with the research team.[30] Data collection and analysis continued in a cyclic process until theoretical saturation was achieved, where no new concepts were noted and the main categories were robust and capable of explaining variation in the data. Data analysis was aided by theoretical memos, which also provided an audit trail of developing categories, and through ongoing peer review. All data has been de-identified, and pseudonyms are used for all participants and their children. This study is reported according to the Standards for Reporting Qualitative Research.[32]

An overarching theory was developed from the data, which describes the changing nature of the relationship between parents and HCPs in the PICU. The theory, *Transitional togetherness*, consists of three stages: *Welcoming expertise*, *Becoming a team*, and *Gradually disengaging*.[33] The findings from the first stage are presented here.

3. Results

Welcoming expertise describes the relationship between parent and HCP when a child enters the PICU until the time when they become aware their child will die. Upon admission, despite the circumstances, there was usually an expectation that the child would survive, so the parent–HCP relationships were built around

prioritisation of their medical needs. At this time, the parents recognised the expertise of the HCP, both in their ability to provide care to the child and for their understanding of 'the system'. This expertise was welcomed at this stage of the PICU journey, such that the HCP took a dominant role in the relationship and the parent took a step back. *Welcoming expertise* consists of two main elements or tasks: *Prioritising survival*, and *Learning the system.*

Prioritising survival describes one of the main tasks a parent undertakes when their child first enters the PICU, and forms the basis of their relationship with HCPs. There were three main elements undertaken to prioritise survival: 'Stepping back', 'Deferring to medical advice', and 'Accepting restrictions'.

The key behaviour parents undertook to prioritise their child's survival was 'Stepping back'. Parents recognised they did not have the skills to care for their child at that point in time but appreciated that HCPs did. This was encapsulated well by Charlie (Hospital 4), who mentioned: "He was in another world now, Liam, where my help and love was beyond what he needed at that point in time. He needed that specialist care in order to try to save his life". Charlie went on to comment that his role was to "take a backwards step, to let the doctors do what they needed to do at that point in time". At this time, most parents still wanted to engage in the various elements of their role as parents, particularly providing love and comfort, remaining hopeful, and being present. However, they often felt unable or unwilling to express these elements because of a desire to prioritise their child's survival. Instead, they perceived their role as one of stepping back and handing over the care of their child to HCPs, in order to protect their child. This willingness to hand over some elements of their role as primary carer and step back was prominent even in the discussions of parents of chronically ill children who were skilled in their child's medical care. Jessica (Hospital 4), the mother of a child with a heart condition, commented that "when it was really early stages and she was incredibly fragile, we did take a step back", with another mother of an ex-Neonatal Intensive Care Unit (NICU) child noting that she only "wanted what was best for my child, and at times that was for me to step aside" (Imogen-Hospital 2). Part of the desire to step aside was the perception that "having non-medical people hanging around all the time is just a distraction" (Imogen-Hospital 2). Parents were concerned they may be "getting in the way of the machinery or just them talking" (Eva-Hospital 1) and made efforts to stay out of the way, to "let [staff] do the best job they possibly can because that's the best chance he's got" (Eva-Hospital 1).

In addition to recognising they did not have the skills needed, many parents were aware that they did not have the medical knowledge required to make informed choices for their child's care. Lucy (Hospital 1) commented that parents "don't know what tests could be done, or should be done, or what the risks are, or…you just don't know." Because of this perceived lack of knowledge, parents often began to defer to medical advice to ensure their child received the most appropriate treatment in a timely manner. This was particularly common for parents of acutely ill children, where the PICU admission was their first experience of serious illness. Parents believed "when it comes to the medical side of things, [staff] know what's the best thing to be done" (Jasmine-Hospital 4). Parents "defer[red] to the medical expertise" (Lucy-Hospital 1) when making decisions for their child, trusting the HCPs' advice was in their child's best interest. In some cases, this extended as far as allowing HCPs to make decisions on their behalf, such as whether to undertake certain procedures or tests or letting them just "do whatever they needed to do to save her" (Abigail-Hospital 2).

As part of prioritising their child's survival, most parents understood and accepted the restrictions that the environment, the staff, or the child's health needs dictated. Parents understood why they could not be present or hold their child, noting "I didn't want to risk anything on her, so it didn't bother me. It didn't make me feel like I was gonna kick up a stink if I couldn't hold her" (Emma-Hospital 1). Parents placed their need for proximity and interaction with their child at a distant second to their child's need for medical care to ensure the best chance of survival. Emma (Hospital 1) noted: "it wasn't a matter of what I wanted, it was what was best for her". It is important to recognise that though parents accepted restrictions required for their child's care, they did not do so gladly or easily. Alice (Hospital 3) was asked to wait outside for hours at a time whilst care was delivered to her child: "I could understand. It was hard, as a parent, not being able to see him…but I knew sort of at the same time that they had to do what they had to do" (Alice-Hospital 3).

The other focus for participants was *Learning the system.* On arrival, many parents had no experience with or understanding of 'the system', defined by bereaved parents as both the PICU and the wider hospital's physical and social environment. For these parents, the hospital, and especially the PICU, was "a foreign environment" (Nate-Hospital 4). They typically had "no idea of the hospital, or the ICU, the nursing staff, the medical staff in general… we had no idea of what to expect or how to expect it and so forth" (Daniel-Hospital 1). In addition to not knowing the routines and culture of the hospital, parents were often unsure "who was who, and who was sort of in charge and who was responsible for doing whatever" (Zara-Hospital 1). They often had no understanding of the roles of the HCPs and were unsure who they could turn to for information or assistance. Most importantly, parents were usually unaware of where and how they fit in as parents. Comments such as "you don't know what you can touch and do" (Nate-Hospital 4) and "you don't know…you know, if you're allowed to approach him or if you have to sit back and wait" (Ryan-Hospital 1) were common, suggesting parents were unsure of their role in the PICU.

Prior experience of the healthcare system formed an important contextual element in our study, exerting significant impact on the way in which parents perceived their roles and relationships within it. Many participants attributed a lack of familiarity and understanding to a lack of prior experience in the system. This is highlighted by Joshua (Hospital 1), who commented: "I've never had to spend time in hospital, so I didn't really know the services available". However, our data suggested that prior hospital experience may not always be helpful for parents, and may even be detrimental. While parents who were HCPs themselves were more familiar with the environment, this did not assist them in establishing their role, because "you come to it first as a parent, and then you come to it as a health professional" (Vicki-Hospital 4). Personal experience in the hospital with a sick child varied in helpfulness. It did not appear to matter whether the experience was of the wards or intensive care, but what did make a difference was whether the child spent time at home between admissions. In most instances, parents of children born in hospital, admitted to NICU, then directly transferred to PICU found their past experiences detrimental, because "I was too used to NICU and just how they used to run, so when everything was done so differently in PICU I didn't like it" (Abigail-Hospital 2). Likewise, this could be particularly detrimental to understanding their role as parents in the PICU. Many NICU parents commented that in NICU, they were very active in their child's care, but "in PICU it just seems to be a case of they don't allow you to or they don't want you to" (Layla-Hospital 4). In contrast, most parents whose children spent time at home between their previous hospital admission and their final PICU journey commented that their prior experience was helpful. These parents felt more comfortable "just doing what we'd done previously, apart from that it was in the PICU and not the ward" (Edward-Hospital 2), suggesting that they felt more familiar with their role as parents in the system.

Learning the system and where they fit into it occurred in many ways. Parents engaged in several behaviours to try to understand the system: they asked questions; asked permission to undertake activities and tested the boundaries of what they could and could not do; watched and mimicked staff; read pamphlets and brochures provided to them; and researched on the internet. Most importantly, parents expected the HCPs to act as experts and guide them through the system. Many participants preferred that the HCP adopted a dominant role in the relationship, with parents expecting them to "sit down with [the family] for a few minutes and just explain to them how it all works" (Imogen-Hospital 2). The HCPs were viewed as being able to give "a little bit more insider information" (Lucy-Hospital 1) so that parents understood the system and were comfortable in it. For many parents, this insider information allowed the PICU to become "more familiar…it became our, sort of, little home" (Nate-Hospital 4), enabling them to eventually recreate a role for themselves as parents.

4. Discussion

The findings from this study provide the first insights into the PICU admission process for bereaved parents and their interactions with the PICU healthcare staff. We suggest that upon admission to the PICU with a critically ill child who subsequently dies, the developing parent–HCP relationship privileges the child's immediate need for specialised medical attention. Findings indicate that in the early stages of the parents' PICU journey, when the gravity of the situation may not yet be evident, parents view HCPs as experts of both the PICU environment and of the child's medical care, and welcome this expertise to save their child. Our findings support and build upon the current understandings of parental admission to PICU, which, to date, have focused solely on the experiences of non-bereaved parents.[24,26,34–37] However, these prior studies have explored the parental experiences of PICU admission generally, rather than focusing on the parent–healthcare provider relationship as it develops during this time. We suggest future research focus on both bereaved and non-bereaved parents' perceptions of their relationships and interactions with PICU healthcare staff during their child's admission. Better understanding these early relationships can help healthcare providers ensure they are appropriately supporting parents and meeting their needs through the stress and confusion of PICU admission.

For parents in this study, the prioritisation of their child's survival and the awareness of the HCPs' expertise meant they were willing to step back and hand over their child's care to the PICU staff. In addition, parents were willing to accept restrictions on their ability to be present or interact with their child, so that life-saving medical care could occur unimpeded. Participants in our study did not view these actions as a loss of their parental role, but instead as protecting the child and contributing towards their potential survival. Our findings appear to be unique amongst the PICU literature; instead, prior studies have found that parents are frustrated and disempowered by such restrictions.[12,25,38] However, it should be noted that in our study, these actions were transient and only occurred during the acute phase of PICU admission when the child was unstable but parents expected they would survive. Once parents realised their child would likely die, a lack of participation in care or proximity to the child was associated with feelings of role loss, similar to other PICU end-of-life care studies.[10,12] It is possible that parents are only willing to step back and give up elements of their parental role when the child is unstable, or when they anticipate survival and believe HCPs are the child's best chance. We suggest future research focus on the evolution of the parental role across the PICU journey, particularly exploring differences in desired roles in times of stability and instability across the child's illness. By understanding the complexities and changing nature of the desired parental role, HCPs can better tailor their interactions with parents across various phases of the parents' journey.

Understanding the hospital and PICU environments and finding a place within it emerged as a key concern for parents in our study. Though Latour et al.[39] found that non-bereaved parents felt well prepared for PICU admission, were advised on what they could expect by the healthcare staff, and were asked about their expectations, this was not the case for the bereaved parents in this study. Most parents described feeling unfamiliar with what they termed 'the system', leaving them feeling lost and unsure of different individuals' roles, and the processes and routines that occurred. Though such feelings of unfamiliarity have been identified in several other studies of parental experiences of both PICU and hospital admissions generally,[26,40,41] it has limited recognition in the PICU end-of-life care literature, identified only by Meert et al.[13] However, this does not necessarily mean that bereaved parents in other studies understood 'the system' better than parents in our study. Instead, the absence of discussion on parents' perceptions and understandings of 'the system' likely reflects the very nature of end-of-life care research: it explores the end of a parent's PICU journey, rather than the beginning, where a lack of familiarity with the system is most concerning for parents.

Given the limited focus on parental understandings of both the hospital and PICU systems within the extant literature, discussions on how parents come to learn these systems and their place within them are understandably lacking. We suggest that familiarity is gained in a variety of ways, from watching and asking questions to utilising internet searches and brochures, though most parents rely on the expertise of the HCPs to help them navigate these systems. Many healthcare providers may also assume that familiarity and comfort within the hospital environment are improved if the parents have previously experienced an admission with a sick child. Surprisingly, our findings suggest this may not be the case. Parents in our study suggest that prior experience of the hospital system, whether through a professional role or having a previously ill child, may not always enhance their familiarity with the hospital environment. Instead, many parents whose children were transferred directly from NICU found their past experiences a hindrance, because their expectations of how the system worked did not eventuate in the PICU. Though the literature acknowledges the potential difficulties ex-NICU parents may face when admitted to the PICU environment,[42] the phenomenon itself remains unstudied. Considering this, our findings should be interpreted with caution until further research is undertaken. Therefore, we recommend future research focus on understanding how parents, both ex-NICU and more generally, gain familiarity with the hospital system so that appropriate supports can be put in place to assist them through this process. In the meantime, we suggest that all parents should be appropriately oriented to the hospital and PICU, regardless of their past experiences or admissions.

The trustworthiness of the findings from our study were enhanced by theoretical memoing, peer review, and theoretical sampling processes which allowed developing concepts to be continually checked with participants to ensure resonance. In addition, adopting a constructivist viewpoint allowed us to embrace the multiple realities of the participants, and co-construct data with them that reflected shared meanings and understandings of these realities. The findings provided here represent these co-constructions, offering one interpretation amongst many that may have been constructed from the data.

Despite these strengths, there are some limitations to our study that must be acknowledged. Firstly, most, though not all, of the parents who participated in our study were Caucasian. However, these participants were from many different cultural backgrounds

and perspectives, reflecting at least some of Australia's cultural diversity.[43] As such, the findings from this study are likely still meaningful for bereaved families both in Australia and in many other culturally and linguistically diverse countries. In addition, this study was undertaken in the context of the Australian healthcare system. Differing admission procedures in different healthcare contexts may impact transferability of our findings. We were also unable to recruit parents with prior PICU experience into our study. It is possible that such parents would have a different experience of the admission process, and so our findings may not hold relevance for them. Finally, bereaved parents participated in this study 6–48 months after their child's death, a timeframe chosen to minimise trauma for parents as much as possible. It is possible that some parents' reflections on their experiences have changed in this time and may not completely reflect their needs at the time of their child's PICU admission.

5. Conclusion

Admission to the PICU with a critically ill and dying child is an extremely difficult experience for parents; fear for their child's life is compounded by the difficulties of navigating an unfamiliar healthcare system. During this time, they often welcome the expertise of the HCPs, both for their ability to provide life supportive care to the child and because they can guide parents through the hospital system. The parent–HCP relationships that develop during the early phases of the child's illness centre around their child's medical needs, with parents stepping back and entrusting their child to these 'expert' medical professionals to provide the best chance of survival. Instead of being involved in their child's care, parents initially focus on learning the system of the PICU and hospital, finding a place for themselves so that they may step back into their role as parents whenever they are able.

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Author contributions

Ashleigh E. Butler, Beverley Copnell, Helen Hall: (1) the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work. (2) Drafting the article or revising it critically for important intellectual content. (3) Final approval of the version to be submitted. (4) Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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