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Research article

The impact of the social and physical environments on parent–healthcare provider relationships when a child dies in PICU: Findings from a grounded theory study

Ashleigh E. Butler[a,b,*], Beverley Copnell[a,1], Helen Hall[a]

[a] School of Nursing and Midwifery, Monash University, Victoria, Australia
[b] Adult and Paediatric Intensive Care Unit, Monash Health, Victoria, Australia

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ABSTRACT

Objectives: This study explores the influences of the paediatric intensive care environment on relationships between parents and healthcare providers when children are dying. It forms part of a larger study, investigating parental experiences of the death of their child in intensive care.
Research methodology: Constructivist grounded theory.
Setting: Four Australian paediatric intensive care units.
Main outcome measures: Audio-recorded, semi-structured interviews were conducted with twenty-six bereaved parents. Data were analysed using the constant comparison and memoing techniques common to grounded theory.
Findings: The physical and social environment of the intensive care unit influenced the quality of the parent–healthcare provider relationship. When a welcoming, open environment existed, parents tended to feel respected as equal and included members of their child's care team. In contrast, environments that restricted parental presence or lacked resources for parental self-care could leave parents feeling like 'watchers', excluded from their child's care.
Conclusions: The paediatric intensive care unit environment either welcomes and includes parents of dying children into the care team, or demotes them to the status of 'watcher'. Such environments significantly influence the relationships parents form with healthcare staff, their ability to engage in elements of their parental role, and their experiences as a whole.

Implications for Clinical Practice

- The physical and social environment of the PICU has significant implications for the development of collaborative parent–healthcare provider relationships when a child is dying.
- In order to support the development of a collaborative parent–healthcare provider relationship, PICUs should endeavour to provide unimpeded parental access to their child, parental self-care facilities such as kitchens, bathrooms and laundry facilities, and the ability to personalise the child's bed space with items brought in from home.
- Negative aspects of the physical environment, including lack of chairs, being excluded from the PICU itself, or small bed spaces, should be avoided as much as possible, as they imply parents are not welcome in the PICU.
- The overall attitudes of the staff and the PICU culture can also be demonstrated through the wording of documents provided to parents to explain the PICU environment and 'rules'. These documents can also subtly influence the relationships that develop between parents and PICU staff.

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[*] Corresponding author at: School of Nursing and Midwifery, Monash University, Victoria, Australia.
E-mail address: Ashleigh.Butler@monash.edu (A.E. Butler).
[1] School of Nursing and Midwifery, La Trobe University, Victoria, Australia.

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Introduction

Within the paediatric intensive care unit (PICU), a critically ill child is almost universally accompanied by at least one stressed and anxious parent. As the child moves through their PICU journey and for some, towards death, parents often remain by their side. The constant presence of parents within the PICU means they will frequently interact with the nurses, doctors and allied health staff who are providing care to their child. Inevitably, most parents develop relationships with these healthcare providers (HCPs) whilst their child remains in PICU, especially when their child is dying. The type and quality of these relationships are generally well understood: when the relationship is positive, a sense of collaboration or teamwork develops between the parent and HCPs, often leading to a sense of role maintenance for the parent (Foster et al., 2013; Yorke, 2011). Such relationships align well with the principles of family centred care, where collaboration and negotiation of roles between parents and HCPs are strongly encouraged (Jolley and Shields, 2009). However, despite awareness and increasing importance placed on the principles of family centred care in paediatric intensive care, collaboration between parents and staff may not always eventuate. Parent–HCP relationships may often be strained, leading to conflict, increased stress, and potentially a limitation of parental presence and interaction with their child (Foster et al., 2013; Meyer et al., 2006; Yorke, 2011).

Though there is an awareness that positive and negative parent–HCP relationships occur, it is unclear why such differences in the types and quality of relationships develop in the first place. Though the attitudes and personalities of both parents and HCPs undoubtedly impact upon the development of these relationships, many studies are beginning to identify the influence of contextual elements such as the physical environment (Macdonald et al., 2012; Meert et al., 2009, 2008; Meyer et al., 2006). These early understandings have demonstrated the ways in which the environment can reduce parents to the status of ‘visitor’ instead of equal (Macdonald et al., 2012). However, research on the importance of the physical and social environment in the development of the parent–HCP relationship when a child is dying is still very limited, with much that remains unknown.

Methods

Objectives

The aim of this study is to explore the impacts of the PICU physical and social environment on the development and quality of the parent–HCP relationship, with findings drawn from a larger study on bereaved parents’ experiences when their child dies in PICU.

Methodology

We followed a constructivist grounded theory approach, which aims to develop a theory about human behaviour and interaction directly from the data itself (Charmaz, 2014). The resultant theory explains the core process occurring within a social context, based upon findings co-constructed from the participants’ personal experiences and the researcher’s interpretations of them (Charmaz, 2014). Given the focus on social interaction and behaviour, grounded theory was the ideal methodology to explore our aim.

Setting

Participants were recruited from four Australian PICUs across three states. Our recruitment procedures varied between sites, but included phone calls from social workers involved in hospital based bereavement follow-up, mailed opt-in and opt-out letters from both the research team and a hospital-based research nurse, and advertisements at bereavement support groups (Butler et al., 2017c). Details of families who were excluded by social workers or who were approached and refused contact by the research team were not provided to us. As such, the overall total number of eligible families or their reasons for refusal remains unknown. Physical characteristics of each PICU are provided in Table 1, to give context to the findings.

Ethical approval

This study was reviewed and approved by all relevant research review committees, and written consent was provided by all participants. In light of the sensitive nature of the research, we employed a number of strategies to protect participants’ psychological well-being, including breaks during the interview process and follow-up phone calls. In addition, all members of the research team were either PICU nurses or midwives, with prior experiences of working with bereaved families. Further details of the strategies we employed are available elsewhere (Butler et al., 2017a). Pseudonyms have been used for all parent and child names, and all data have been de-identified.

Participants

Twenty-six bereaved parents, representing 18 deceased children, participated in the study 6–48 months after their child’s death. We used purposive sampling to invite the first five participants to take part in the study, based solely on the fact that they had a child die in one of the study PICUs. Theoretical sampling techniques, including selecting participants based on various characteristics identified as important in the data (for example, the child’s age, type of death, type of illness, or prior hospital experience), adapting interview questions, and adding additional PICUs,

Table 1
Hospital environmental characteristics.

Hospital	Number of beds	Locked unit	Waiting rooms	Parent lounge	Toilet/bathroom in PICU	Parent bedroom	Parent kitchen	Private rooms	Visitation rules
1	6*	Yes	Outside	Outside	No	Outside	Kitchen outside	Limited number	2 visitors at a time. Restricted visiting hours. Unrestricted parental access
2	36	Yes	Outside and inside	Inside	No	Outside	Kitchenette inside, kitchen outside	Limited number	2 visitors at a time. Restricted visiting hours. Unrestricted parental access
3	19	Yes	Outside	Outside	No	Outside	Limited kitchenette	Limited number	Unknown-hospital closed
4	13	Yes	Outside	Inside	Unclear	Unclear	Limited kitchenette	Limited number	3 visitors at a time. Restricted visiting hours. Unrestricted immediate family access

* Connected to adult ICU with extra overflow beds available when required.

Table 2
Family characteristics in each hospital.

Hospital	Families
1	*Evelyn and Joshua:* Infant, died 1 year and 6 months prior to participation. Admitted to PICU with congenital heart disease. Life support withdrawn after 9 days. Prior ward experience
	Emma: Infant, died 1 year and 4 months prior to participation. Admitted to PICU post cardiac arrest at home (Sudden unexplained death in infancy). Life support withdrawn after 2 days. Nil prior hospital experience
	Lucy and Hudson: Toddler, died 13 months prior to participation. Admitted to PICU in cardiac arrest, presumed sepsis. Resuscitation attempts ceased after 2 h. Nil prior hospital experience
	Hannah and Daniel: Teenager, died 8 months prior to participation. Admitted to PICU with metabolic condition. Life support withdrawn after 5 days. Nil prior hospital experience
	Zara and Ryan: Teenager, died 1 year and 8 months prior to participation. Admitted to PICU with multi-organ failure. Life support withdrawn after 3 days. Prior experience of hospital system (healthcare worker-mother)
	Eva: Teenager, died 3 years and 8 months prior to participation. Admitted to PICU with anaphylaxis. Life support withdrawn after 6 days. Nil prior hospital experience
	Isabelle: Teenager, died 2 years and 10 months prior to participation. Admitted to PICU post cardiac arrest. Life support withdrawn after 11 days. Prior experience of hospital system (healthcare worker-mother)
2	*Abigail:* Infant, died 1 year and 10 months prior to participation. Admitted to PICU with congenital heart disease. Life support withdrawn after 8 weeks. Prior NICU experience
	Imogen: Toddler, died 4 years prior to participation. Admitted to PICU with multi-organ dysfunction, presumed sepsis. Life support withdrawn after approximately 2.5 weeks. Prior NICU experience
	Piper and Edward: Teenager, died 3 years prior to participation. Admitted to PICU with neurological injury. Life support withdrawn after 3 weeks. Prior ward experience
3	*Alice:* Toddler, died 1 year and 2 months prior to participation. Admitted to PICU post accident. Life support withdrawn after 5 days. Nil prior hospital experience
4	*Vicki and Nate:* Infant, died 2 years and 10 months prior to participation. Admitted to PICU post cardiac arrest at home (Sudden unexplained death in infancy). Life support withdrawn after 6 days. Prior hospital experience (healthcare worker- mother)
	Layla: Infant, died 7 months prior to participation. Admitted to PICU with neurological injury. Life support withdrawn, unclear timeframe. Prior NICU experience
	Sarah and Connor: Infant, died 2 years prior to participation. Admitted to PICU post cardiac arrest at home (Sudden unexplained death in infancy). Life support withdrawn after 3 days. Nil prior hospital experience
	Zoe and Charlie: Infant, died 3 years prior to participation. Admitted to PICU with single organ failure (non-cardiac). Life support withdrawn after 2 days. Nil prior hospital experience
	Jessica: Infant, died 2 years and 6 months prior to participation. Admitted to PICU with congenital heart disease. Life support withdrawn, unclear timeframe. Prior ICU experience
	Jasmine: Infant, died 1 year and 6 months prior to participation. Admitted to PICU with single organ failure (non-cardiac). Life support withdrawn after 5 days. Nil prior hospital experience
	Erin: Toddler, died 3 years and 6 months prior to participation. Admitted to PICU with congenital heart disease. Life support withdrawn, unclear timeframe. Prior NICU experience

were then used to explore gaps in the developing categories, consistent with grounded theory methods (Charmaz, 2014). Characteristics of the participating families are provided in Table 2.

Data collection

Data collection included both interviews and document analysis. Bereaved parents participated in audio recorded, semi-structured interviews lasting 90–150 minutes, in a location of the participants' choosing. The first author, a PICU nurse who had no prior relationship with any participant, conducted the interviews over 18 months between 2015 and 2016. Early interviews were based on an interview guide, with questions changing throughout the data collection process to focus on key categories and themes as they developed. Interviews continued until data saturation was achieved. Field notes were made of conversations held after the recorder was turned off, with participant permission. In addition, the principles of theoretical sampling led us to gather brochures from each hospital that explained the PICU environment to the parents, to further explore developing contextual elements.

Data analysis

We analysed data from both transcribed interviews and documents using the coding and constant comparative analysis principles outlined by Charmaz (2014). After entering the data into NVivo 10, we used open coding techniques, constructing codes that captured meaning within the data. We then used the constant comparison techniques and focused coding to develop categories and compare actions, events and concepts, until three key phases were identified: *Welcoming expertise, Becoming a team*, and *Gradually disengaging*. From these phases, we engaged in theoretical coding and memoing, and developed a theory that could explain the changing nature of the parent–HCP relationship when a child dies in PICU, called *Transitional Togetherness* (Butler et al., 2017b). The three key phases, the categories and processes they contain, and illustrative data are presented in Table 3. In addition, we also identified several contextual elements which exerted influence over the quality of the relationships that developed. The most significant contextual factor, the PICU environment, is presented here.

Findings

Relationships between parents and HCPs do not develop in isolation. Instead, as demonstrated by our findings, these relationships develop in the context of the physical and social environments of the PICU. We found that the PICU context had significant impacts on parent–HCP interactions, subtly influencing and reinforcing the type and quality of relationships formed. These environments could either enhance the development of a

Table 3
Development of phases and respective categories.

Data	Code/sub-category	Category	Phase
"I wanted what was best for my child and at times that was for me to step aside so the other person can be unobstructed to do their job"	Stepping back	Prioritising survival	Welcoming expertise
"When it comes to the medical side of things, they know what's the best thing to be done"	Deferring to medical advice		
"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"	Accepting restrictions		
"I think it took maybe a day and a half or 2 days just to sort of realise 'Oh, the nurses gotta do their job, and the doctors have to you know, see what they can figure out', and then once you get sort of. . .you feel a bit comfortable with them, then you can freely just go up and, you know, say hi or hold his hand. Talk to him"	Finding a place	Learning the system	
"The first time a parent comes in with their child ……. before they leave, that one of the nurses on the team that day who is likely to have something to do with that family over the next days or weeks to go and sit down with them for a few minutes and just explain to them how it all works"	Relying on healthcare providers		
"I remember just thinking that was just our role, we just sit there and support him and be with him, and look after him as much as we could"	The parental role	Constructing roles	Becoming a team
"Making sure things are still stable, and making sure that their drugs are given at the right time, and if anything is out of the ordinary to call the appropriate people. Cuddle the baby when they can"	The healthcare provider role		
"It felt like we were all working on the same team"	Working on the same team	Negotiating collaboration	
"I couldn't feed him, I couldn't change his nappy, I couldn't bath him, couldn't pick him up whenever I wanted to, so in that sense, I felt that my role as a mum was taken away ……. I just had to sit there and watch the nurses do it"	Becoming a watcher		
"He was just fantastic, you know, he was, calm, collected, um. . .genuine, he was probably very patient with me, you know, because I wanted to know everything as it was happening"	The 'good' healthcare provider	Judging healthcare providers	
"You'd expect a doctor to be a bit more sympathetic and a bit more compassionate. He was none of that"	The 'poor' healthcare provider		
"They were just like 'however long you need, you just take' and so the nurse actually said, 'would we like to do the last bath?', and you know, she helped us"	Being supported	Saying goodbye	Gradually disengaging
"With the funeral directors, they said, "You can take as long as you like." With that you didn't have that in PICU. They didn't say that to you. So in a way, they didn't say it was rushed but you felt like you were being rushed"	Lacking support		
"It felt like everyone just left you. You know, and then you've gotta sort of work out your own way sort of. . .do we stay here, do we go?"	Being unsure	Going home	
"It just sort of felt like … there was no support, it was just like okay. . ."We're gonna take Olivia now" and that's it, the doors closed"	Feeling a void		
"She brought me like the books and a bear and a candle and stuff like that. And, yeah, she came for a couple of follow up visits, just talked to me"	Maintaining a supportive connection	Seeking supports	
"It was just like well the hospitals forgotten, you know, they've cut all ties and they've forgotten and they've moved on and it's like well, what now? You just sit on the couch and go "What now?""	They've forgotten you		

collaborative parent–HCP team or indicate that parents were generally unwelcome in the PICU. The impact of the PICU environment was particularly prominent with respect to *Negotiating collaboration* within the parent–healthcare provider relationship, a category that occurred during the second phase of the theory, *Becoming a team.* When *Negotiating collaboration* with healthcare staff, parents generally described feeling like they were either *Working on the same team* or *Becoming a watcher* (as outlined in Table 3). The impacts of the PICU environment on each of these processes are discussed below, alongside a discussion of the impact of the brochures provided to parents by the PICU.

Working on the same team

The concept of *working on the same team* describes a positive, collaborative relationship that formed between parents and HCPs. This type of relationship developed when complementary parent and HCP roles were adopted, and the parent was supported and encouraged to participate in their child's care to the extent they desired. There were many elements of both the physical and social environments that fostered the development of a collaborative relationship, typically through demonstration that the parent was a welcomed and valued addition to the PICU.

Primarily, the development of a collaborative parent–HCP team was fostered by the provision of a welcoming atmosphere for parents. Easy, unrestricted access to their child allowed parents to "come and go however we pleased" (Alice, hospital 3), ensuring parents felt welcomed in the PICU. This also helped to facilitate parents physically being present with their child to undertake their roles and participate in the healthcare team. Parents commented favourably on unobstructed access to the PICU, because "you could leave but easily get back to your child, there wasn't a……locked door separating you" (Piper, hospital 2). If coupled with a positive social environment characterised by a welcoming staff attitude, parent–HCP relationships were more likely to be positive, with parents commenting "I don't think there was ever a time we were made to feel like we shouldn't be there" (Daniel, hospital 2). In addition, a welcoming environment was demonstrated when parents were provided with comfortable chairs, facilitating prolonged stays at their child's bed space. Many parents commented on being provided with a "big chair in the ICU, it folded down into an armchair" (Ryan, hospital 1) that allowed them to be present, sit comfortably, and safely hold their child. The provision of resources such as comfortable chairs and meals did not contribute to positive parent-staff relationships for all parents, however, with Evelyn (hospital 1) commenting positively on the comfortable environment of the PICU but still noting that she "felt that my role as a mum was taken away" by a lack of collaboration with the PICU staff.

In addition, the provision of resources for parental self-care also helped to foster a positive relationship. Parents appreciated when facilities for showering, laundry, or breaks were provided. This was highlighted by Isabelle (hospital 1), who commented that "knowing that different services were there was great, like knowing……there was like a parent's room or something where you could have a shower or do laundry" was useful because it allowed her to "get out and get [her] sanity" back after the perceived insanity of her child's bed space. For many parents, these resources enabled them to care for themselves when they otherwise would not have. Piper (hospital 2) noted: "when your kids are in that place, your health is not necessarily your top priority, it's them. But……in the parent lounge there was actually a shower, so you could go shower." When the PICU environment enabled parents to look after themselves, they were better able to participate in the care of their child, and therefore in a collaborative relationship with HCPs. This concept was encapsulated by Edward (hospital 2), who noted that "they were also looking after us, so we could better look after Ethan." The provision of food and drinks within the PICU was also important in enabling parental participation. Parents appreciated when the PICU "had coffee and tea and biscuits and toast or muffins and cereal and snacky food" (Connor, hospital 4), because "we didn't have to say 'okay we need to go down to the cafeteria'…we didn't need to leave Olivia" (Daniel, hospital 1).

Finally, many parents discussed staff encouragement to bring items in from home, which enhanced their feelings of comfort and ownership of the environment and supported the development of a collaborative parent–HCP relationship. For example, Erin (hospital 4) mentioned that the staff "allowed us that flexibility to make it [the child's bedspace] ours a little bit", so her daughter's room had "a lot of toys" and "four butterflies that were dangling from one of her machines". Other parents commented on having the television on for their child "to make it feel like they're at home because if they were at home, you'd have your TV on" (Layla, hospital 4). This type of behaviour helped demonstrate that the PICU was not solely the domain of HCPs, but that parents also belonged within it.

The concept of working together as a collaborative team could also be reinforced by the documents provided to parents in the PICU, though to varying degrees. The welcome brochure provided to parents in one PICU, for example, clearly set up the expectation that parents were part of the healthcare team by stating that the PICU was "committed to providing safe, high-quality family centred care and working in partnership with you". The document then stated that parents "play an important role" in the care provided and that their involvement was welcomed. In addition, this document outlined the hospital system to parents, identified ways they might be involved in their child's care, and described how they could also care for themselves when their child was in PICU. Similar documents provided by one of the other PICUs also mentioned that they "welcome the involvement of parents", suggesting the possibility of parental participation in care.

Becoming a watcher

When a collaborative relationship did not develop, parents described *becoming a watcher*. The unwelcoming social and physical environment of the PICU furthered this feeling, displacing parents from many elements of their parental role and reinforcing the notion that they were simply 'visitors' in the HCPs' workplace. These elements often contributed to the development of a negative, unequal parent–HCP relationship.

In our study, many parents commented on the prohibitive nature of the PICU environment, particularly to their presence with their child. Often, parents were met with locked doors and complicated entry procedures, impeding their entry into the PICU. Piper (hospital 2) commented on the difficulties she faced each time she attempted to be with her child: "When we were heading in, you'd hop off at the 5th floor and go press the button and stand in front and identify yourself and then you'd get through to a waiting area, and you'd have to wash your hands and everything in that area, and then you would buzz [another doorbell] and you know, like, there would be times where 'well, the doctors are with her right now, so please wait'." For most parents, these difficult entry procedures hindered the development of a positive, collaborative parent–HCP provider relationship because they hindered the parents' ability to physically be present to form relationships with the staff, let alone participate equally in the care of their child. A small number of parents, however, did not feel that such restrictive entry procedures hindered their relationship with the PICU staff or their role as a parent. Eva (hospital 1) disliked having to "rely on someone else coming out the back door to give you an opportunity to run in", but still maintained a positive relationship with the staff, commenting that they gave her "the opportunity to do all that I needed to do for him" as a parent.

Even after parents had gained access to the PICU, the social environment often continued to make them feel unwelcome. Many parents recounted stories of being 'asked' to leave for procedures, ward rounds, or simply because it was past the designated visiting time. During the initial admission period, most parents accepted this restriction in order to ensure their child received the best care possible: "They were trying to get him stable, and everything all stable before we could go back in the room. Because they doing so much with the drips and the ventilator and stuff…there was a room full of people, so they didn't want us in there, sort of, while everything was going on ...... 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). However, after the child had been stabilised, most parents felt unwelcomed and lacking control when they were excluded from the PICU. For example, Lucy (hospital 1) described the moments when her son was intubated, and mentioned that "the clear message...implication...was we needed to leave, and, you know...so we were sort of sent away." This was mirrored by Jasmine (hospital 4), who commented: "I just remember them telling me that I had to leave because they were going to put some breathing tubes in and stuff, and I wasn't allowed to be there for that." These elements of the physical and social environments reinforced the idea that parents were visitors within the PICU and staff had control over their presence, contributing towards the development of an unequal parent–HCP relationship.

The physical environment often also made prolonged stays uncomfortable for parents, further hindering their ability to be present and participate in care. This was highlighted by Imogen (hospital 2), who commented that "the whole way it's set up makes you feel so uncomfortable to be there for very long, so you just come in, stay for a short time, and you don't wanna overstay your welcome, so you go." Often, parents felt uncomfortable because there were no resources available for them. Imogen (hospital 2) noted that "they picked the most uncomfortable chair you could have ever picked, like a rotten hard flat back, high back garden chair." In addition, though staff had access to a bathroom or kitchen, the same amenities were frequently not provided for parents. Zara (hospital 1) felt uncomfortable at having to go to the bathroom, because "there wasn't a visitors' toilet in the actual ICU, so you have to go, like...go out and then buzz to come back in, and it's like 'Sorry, it's me again!'...... it's embarrassing." In addition to a lack of resources, the environment itself was often unpleasant. One mother commented that she always felt "crammed, because it's really squishy in all of those rooms" (Erin, hospital 4), with another noting that there were always "all the lights, all the time, and you've got medical equipment everywhere" (Alice, hospital 3), which made any attempts to stay in PICU so uncomfortable that they often left, hindering the development of a positive parent–HCP relationship. This was not the case for all parents, however, with Joshua and Evelyn, Sarah and Connor, and Zoe and Charlie all commenting positively on the resources provided to them but still feeling "like an observer most of the time" (Connor, hospital 4) their child was in the PICU because they were not permitted by staff to interact with their child as they desired.

For many parents, the equipment hindered their ability to touch or hold their child, or participate in care, therefore inhibiting their integration into the child's care team. A number of parents commented on the difficulties of being close to their child's bed because of the placement and size of the equipment. This was highlighted by Connor (hospital 4) who commented that "it was very difficult to get to beside her because there was that many...pieces of machinery." As a result, Connor felt he "couldn't full on cuddle her, because she still had plenty of stuff attached to her", which inhibited some of the elements of his role as a parent as he saw it. Many parents also felt that life-supportive machinery was occasionally deliberately used by staff to prevent them from holding or interacting with their child. Imogen (hospital 2) mentioned wanting to pick up and cuddle her critically ill child, but noted there was "no willingness [from the staff]......it's like it's a pain in the neck, some would ask 'do you really wanna do it with all these tubes'". In addition, Abigail (hospital 2) recounted how she "got a very stern talking to about not to touch her", because her child was connected to life-sustaining technology. For Abigail, this demonstrated that the staff "had more control" over her child than she herself did, which negatively impacted upon her relationships with staff caring for her child.

Though parents did not specifically mention the wording of the documents they received, they did mention a perception that the PICU environment was generally unwelcoming and did not make them feel included in their child's care. Introductory documents, forming part of the physical and social environments may have, at least in part, contributed towards parents' perceptions of being unwelcome. For example, the introductory brochure provided by one PICU failed to mention the involvement or importance of parents in the care of their child. Instead, the document mentioned that the 'whole team' would work to provide 'the very best care to your child', signifying the status of staff as expert and excluding parents from the care team. In addition, this document claimed the PICU environment as the domain of the staff by mentioning that the child would be cared for "in <u>our</u> PICU" (author emphasis), rather than the phrasing "in <u>the</u> PICU" used by documents in other hospitals. The document also "strongly encourage[d]" parents to take breaks away from the PICU, implying that parents should not be present in the ICU for long periods, potentially impacting upon how welcome they felt to be present with their child to enact their parental role. The use of the term 'visit' when referring to parental presence with their child further implies that parents were not considered equal members of the healthcare team. These subtleties within the PICU documents demonstrate the overall attitude the PICU culture espouses towards parents, potentially making them feel unwelcome and unequal from the moment they enter the PICU.

Discussion

Our findings demonstrate the substantial impact the environment may have on parents' ability to engage in various elements of their parental role, and subsequently, on their ability or expectation to form collaborative relationships with HCPs when in PICU with their child. For the parents in this study, the environment included both physical aspects, such as ease of access or the provision of self-care facilities, and the social environments created by staff attitudes and actions. Though the parents' length of stay varied greatly (hours to weeks), almost all parents offered a discussion on the impact of the environment on their roles, their ability to be included in their child's care team, or their experiences overall. It was clear from these discussions that the environment could either welcome parents as an equal member of the healthcare team, or could designate parents as 'visitors'.

The negative impacts of the PICU environments, both physical and social, have been well documented. Parents in previous studies have identified a lack of space, poor quality chairs, complicated entry procedures, lack of privacy, and the presence of technology as the biggest detriment to their overall experience when their child was dying (Falkenburg et al., 2016; Latour et al., 2011, 2009; Majdalani et al., 2014; Mattsson et al., 2014; Meert et al., 2008). Similar concerns have been identified as areas in need of improvement by family members of adults in an ICU environment (Abbott et al., 2001; Lloyd-Williams et al., 2009; Obringer et al., 2012) These concerns are mirrored by most parents in our study, who also identified other negative elements such as a lack of resources for parental comfort. However, these negative impacts were not the only way that parents in this study viewed the PICU environments. Instead, many parents also identified several key elements of the PICU environment that positively enhanced their time with their child, including provisions for sleep and self-care. The identification of positive environmental elements within the PICU end-of-life care literature is limited, but generally consistent with our findings (Mattsson et al., 2014; Meert et al., 2008). We suggest that future studies move away from exploring negative or unhelpful elements of the environment, and instead focus on further exploring or improving those elements that parents find helpful. In this way, PICUs may not only eliminate negative aspects of the environment but may also implement or enhance those elements that have been identified as potentially beneficial.

Our findings have also demonstrated the impact the physical and social environments of the PICU can potentially have on the development of collaborative parent–HCP relationships. Though this concept has not been discussed by parents within other studies directly, it has been observed. Macdonald et al. (2012) found that the PICU's physical and social environment could transform the parents into 'visitors', but could also be positively used to reduce family role displacement. Their findings, which closely reflect our own, suggest that when parents are 'asked' to leave the PICU, or when they are told not to touch the equipment, they become visitors, rather than parents (Macdonald et al., 2012). However, Macdonald et al. (2012) suggest this process could in part be negated by the social environment of the PICU; when the staff encouraged parents to decorate their child's bed space, they minimised the transformation of the child into a patient, and therefore also reduced the displacement of parents into the role of visitor. This was similar to our own findings, with parents suggesting that such personalisation of the child's bed space helped them to feel welcomed as equal members of the healthcare team. Given this is the first study to explicitly demonstrate the impacts the environment can have on the development of a collaborative parent–HCP relationship, further research is needed to explore their relevance to other PICUs or circumstances, such as when the child survives.

In the meantime, we suggest that family centred care principles be used to guide the development of both new and existing PICU environments. The negative factors identified by parents in this study should be minimised as much as possible in order to promote and support collaborative parent–HCP relationships. The creation of a family-friendly environment equipped with resources for parental self-care, such as toilets and kitchens, as well as easier entrance procedures, may significantly help parents and families to feel welcomed and included in their child or loved one's healthcare team. Family centred care principles also advocate for hospital policies and procedures that support and include family involvement and collaboration in care (Institute for patient and family centred care, n.d.; Jolley and Shields, 2009). In order to achieve this goal, individual PICUs should explore both their physical layout and their policies and procedures, with attention given to elements that may exclude or restrict parental or family presence, such as limitations on overnight visitors or presence during procedures.

When considering the PICU environment, attention must be given to all elements that may contribute, not just the physical components. Our findings suggest that the brochures and pamphlets available to parents in the PICU have the potential to subtly influence the types of relationships they might expect with HCPs. This has not previously been described in the paediatric or adult ICU literature. Primarily, the language utilised within these documents reflects the attitude of the hospital and PICU management, and by extension, the attitude of the PICU staff, towards parental presence and participation in the child's care team. When given to parents on their arrival to the PICU, these documents may relay a powerful message about what they might expect for their own role and place in the PICU. Unfortunately, as many of the parents in our study were unable to specifically recall the documents they were given in the PICU, we were unable to explore their personal perceptions of these brochures, and so their actual impact remains unknown. We suggest, therefore, future research focus on parents' perceptions of documentation in the PICU, and the extent to which these impact on their expectations of their role within the healthcare team. PICUs should also review their own documents provided to parents, ensuring they utilise family-centred language as much as possible. This may help to display a welcoming and open attitude towards parental presence in the PICU, which is then modelled by both senior staff and espoused in the overall philosophy of the PICU.

Limitations

There are a number of limitations in our study that must be considered when interpreting our findings. Though this study was undertaken across multiple Australian PICUs across 3 states, the impact of the broader Australian healthcare climate and culture may reduce transferability of these findings to other countries or healthcare contexts. In addition, though every effort was made to include a wide range of families, most of our participants were of Caucasian descent, and so our findings may not have meaning for non-Caucasian families. Finally, we were unable to recruit any parents with prior PICU experience into our study, which may have influenced our findings. However, our findings were strengthened by prolonged engagement in the field, the use of theoretical memos, and via the constant comparative analysis technique, which allowed constant checking of our developing categories with participant families. This study is reported according to the Consolidated Criteria for Reporting Qualitative Research (Tong et al., 2007), contributing to the trustworthiness of our findings.

Conclusion

Within the PICU, parent–HCP roles and relationships may be influenced by many aspects of the physical and social environment. These elements may be as simple as the provision of comfortable chairs, or as complex as the wording of various orientation documents provided to parents upon arrival. When combined, these contextual elements impacted upon the parents' perspectives of their place in the PICU, influencing whether parents viewed themselves as valued team members or simply visitors to the PICU, and on quality of the relationships they formed with the PICU healthcare staff. Given the impact these relationships can have on the parents' experiences, developing an understanding of these contextual influences is crucial. Only then can HCPs work to mitigate any negative influence such contextual elements may pose, in order to support the development of positive parent–HCP relationships in the PICU.

Conflicts of interest

None to declare.

Ethical statement

Ethical approval provided by three health services, with overarching approval provided by Monash University Human Research Ethics Committee: CF15/291-2015000145. Informed written consent was provided by all participants.

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Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at https://doi.org/10.1016/j.iccn.2017.12.008.

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