

The experience of long-stay parents in the ICU:
A qualitative study of parent and staff perspectives

Sophie Geoghegan¹, MA; Dr. Kate Oulton¹, PhD; Dr. Catherine Bull¹, MRCP; Dr. Joe Brierley¹, MD;

Dr. Mark Peters^{1,2} FRCPCH, PhD; Dr. Jo Wray¹, PhD

¹*Great Ormond Street Hospital NHS Foundation Trust, London UK*

²*Institute of Child Health, University College London, London UK*

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Corresponding author

Jo Wray

[Great Ormond Street Hospital](#)

[Room 4052, Barclay House \(Level 4\)](#)

[37 Queen Square](#)

[London, WC1N 3BH](#)

[+44 \(0\)20 7405 9200](#)

Abstract

Objective: Meeting the needs of parents of critically ill children is increasingly being recognized as an important factor in the child's clinical outcome as well as the implications it has on future parenting. Little is specifically known about the experience of parents who have a child in the Intensive Care Unit (ICU) for a prolonged period. Our objective was to understand the experiences of this group to assist the identification of mechanisms for providing support.

Design: Qualitative study based on semi-structured interviews. Data were analysed using the Framework approach.

Setting: The study took place in a tertiary pediatric hospital containing 3 ICUs: Pediatric Intensive Care Unit (PICU), Cardiac Intensive Care Unit (CICU), Neonatal Intensive Care Unit (NICU) (ICU will be used to encompass NICU, CICU and PICU for the remainder of the paper).

Participants: Seventeen members of staff and twenty-six parents of a child who had a long-stay in one of the three ICUs.

Interventions: Semi-structured, tape-recorded interviews.

Main Results:

Analyses identified two overarching themes, 'parent process' and 'parent/staff interface', and 6 sub-themes: adjustment; normalisation/institutionalisation; conflict; involvement in child's care; individualised care; and transition. Themes have been modelled to account for the parental process during a long stay in ICU and the potential implications on the relationship and interactions between parents and staff. Findings are presented from the data related to the 'parent process' and 'parent/staff interface'. Inclusion of an element in the model related to staff indicates where support mechanisms should be focused.

Conclusions: Over time, long-stay families will likely become more familiar with the environment of the ICU, more knowledgeable about their child's medical needs and more familiar with the staff looking after their child. This has a number of implications for staff working in the ICU.

Introduction

Although the majority of patients in the Pediatric Intensive Care Unit (PICU) have a stay of less than three days (1), improvements in life-sustaining treatments have resulted in increasing numbers of children being hospitalized for longer periods of time. A child's admission to the ICU induces high levels of stress and anxiety in parents (2-10). Meeting their needs is increasingly being recognized as an important factor in the child's clinical outcome and as having implications for future parenting (11). Despite this, little is known about the experience of parents who have a child in the ICU for a prolonged period.

Research to date has largely explored parental needs, stressors, coping strategies and comparisons between parental and staff perceptions of PICU ward practices, e.g. ward rounds and transitions. Parents cope with the stress of being in the PICU in different ways (12) and adopt different roles when faced with a stressful admission (2). Research has consistently identified the alteration in parental role as a stressor (11,13). Active participation is a key coping strategy for parents in the PICU – when children are critically ill, parents strive to be present and participate in the care of their child (14-16). Parental participation may decrease tension between staff and the family and improve communication (17). Nurses have a key role in facilitating parental involvement in their child's care (14, 18-19).

Following their admission to the PICU, parents require an adjustment period (20). Levels of anxiety experienced at the time of admission may stabilize over the following days (12, 21). Parents adapt to their new environment, acclimatising to the PICU setting, language and procedures. They may begin to ask more questions, expect to be involved in decisions regarding their child's care, and wish to participate in the delivery of care at the bedside (2,22-24, 16). Parents' initial concerns about the environment and their child's condition begin to shift to other issues involved with their child's hospitalisation (6, 25). Over time, staff communication and behavior may become a stronger

determinant of parental stress (12) and conflict may be more common when a stay is prolonged (26).

It is apparent that during the course of a PICU admission parents' needs and focus change (8). Extant research is primarily concerned with patients who have an average length stay in the ICU. Whilst parents of long-stay patients (LSPs) have been included within study populations, little is specifically known about their experiences. Our objective was to gain a deeper understanding of the experiences of this group which will assist in identifying possible mechanisms for ensuring parents of LSPs are appropriately supported by staff working in the ICU. The data reported here are part of a broader study looking at long-stay in paediatric critical care and the impact on both staff and parents. Results of the impact on staff have been reported previously (27).

Materials and Methods

Setting

The study was conducted in a tertiary pediatric health care setting containing 3 units providing intensive care; NICU, PICU and CICU. Local definitions of long-stay were 28 days for PICU and NICU and 14 days for CICU. Due to the nature of the hospital, the NICU is distinct from the NICU of a hospital with a maternity ward; often neonatal patients have complex needs or require specialist surgical care, thus their ICU course has a lot in common with patients in the PICU. Cross-staffing of medical and allied-health professionals (AHPs) occurs in the PICU and NICU at this hospital.

Participants

A purposive sampling frame was used to recruit medical, nursing and AHPs working in 3 ICUs and adjoining wards. Lead clinicians were sent study information to share with their teams.

Parents were purposively recruited to take part in the study if their child had a stay in one of three ICUs (NICU, PICU or CICU) for a duration of at least 2 or 4 weeks, depending on local

definitions of long-stay (see above) Parents were initially approached with information about the study by local specialist nurses who obtained consent to pass on their details to the research team. Written informed consent was obtained from all participants prior to commencing interviews. To avoid participant identification, quotes used to illustrate findings will be denoted by (S) for staff participants and (P) for parent participants.

Interviews

All interviews were conducted face-to-face by a single researcher and took place in parents' own homes or in quiet rooms across the hospital. Interviews lasted 30 - 60 minutes for staff, and 1 - 2 hours for parents. Each was audio recorded and transcribed verbatim. Topic guides were used to provide general structure, although participants were encouraged to influence the direction of the interviews. Within the broader study looking at the impact of long-stay, staff were asked to reflect on the needs and care provided to LSPs, and how it compares to average stay patients and families. Parents were asked to give an account of their experience of having a child in ICU, particular challenges they faced, and how they were supported during their time there.

Qualitative Data Analysis

Qualitative data were analysed using the Framework approach (28). This structured approach is designed to involve a team of researchers in the analysis process which involves five distinct stages: familiarisation; identifying a thematic framework; indexing; charting; mapping and interpretation. It allows themes to develop both from the research questions and from the narratives of research participants (29). Analysis involves the construction of a series of "frameworks" or grids into which summarised qualitative data are entered under descriptive headings. These descriptive headings were generated by the research team after careful examination of the transcripts. Data from each transcript was then entered individually into the framework and the completed frameworks were then used to extract key themes and the relationships between themes explored.

Ethical approval for the study was granted by the NRES Committee London-Westminster (REC reference number: 13/LO/1591).

Results

Findings

Seventeen staff members participated in the study: 3 consultants, 7 nursing staff and 7 AHPs. Four of the participants were male and thirteen were female. The majority of participants had been working in pediatric critical care for at least two years; the range was between 9 months and 21 years. Eight of the participants were aged 41-50 years, 4 were aged 31-40 years and 5 were under 30 years of age. Table 1 provides a summary of staff participants.

Table 1. Staff participant summary

TABLE 1

Specialist nurses contacted 45 families, 18 of whom agreed to participate in the study – 5 declined participation and 22 did not respond to the researcher. In total, 26 mothers and fathers of 18 children who had a long stay in ICU participated in the study. All children had stayed in one of the three ICUs over an 18 month period and were aged between new born and two years and four months at the time of their admission. Three of the 18 children had had a previous ICU stay. Table 2 provides a summary of parent participants.

Table 2. Parent participant summary

TABLE 2

Analyses revealed that every family is different in how they cope and adapt to being in the ICU for a prolonged period of time: *“Over time, for some of those families it can actually get better. They’ve got more relationships on the ward with staff...they get on well with the nurses... they’re used to what happens on the ward. Other families...it can be really distressing then to still be here for*

a long time...then their needs and concerns can escalate..." (S8). Parents in this study adopted different roles and coping strategies during their time in the ICU. Some were more passive: *"I was quite a passive person... the way you don't want to speak up and ask..."* (P2), whilst others took on a more active role: keeping records of nurse names and drugs administered; coordinating care providers; contacting other hospitals to check bed capacities; trying to instil a sleep pattern; making the ward space homely. Despite differences between the circumstances surrounding their admission and the unit they were admitted to, there were a number of things which characterised parents' experiences of being in the ICU for a prolonged period.

Analyses identified two overarching themes, 'parent process' and 'parent/staff interface', and 6 sub-themes: adjustment; normalisation/institutionalisation; conflict; involvement in child's care; individualised care; transition. Themes have been modelled (see figure 1) to account for the parental process during a long stay in ICU and the potential implications on the relationship and interactions between parents and staff. Inclusion of the staff element indicates where support mechanisms should be focused. The results section presents findings related to the 'parent process' and 'parent/staff interface', recommendations relevant to staff mechanisms for providing support are addressed in the discussion.

Figure 1. Proposed model of the parent process and the potential impact on parent and staff interface

FIGURE 1

PARENT PROCESS

Adjustment

Some participants spoke about the adjustment that long-stay families make after the initial acute period in the ICU: *"it changes from an acute distress and shock and trauma of having a child in*

intensive care; some of that is still there but I think they adjust to being in intensive care, and then it's more the challenges of being in that environment on a long-term basis" (S4). This participant described the transition when long-stay families must address their own needs and those of other family members: "they've had the acute shock period; they're then realising they can't sustain the level of visiting or maybe the intensity of just being on the ward for all that time and they have to review that but that's very hard for them...because their child's still in intensive care" (S4). One mother described: "If you went out you kind of felt guilty...like you were putting your own needs before your child" (P10).

Normalisation/Institutionalisation

Following this period of adjustment most parents began to feel more settled in the ICU. A number of participants described their "routine" whilst on the ICU which centred on being present for key medical points – ward rounds and nurse changeovers, and taking breaks away from the ICU to have meals: *"our days were quite regimented. We'd go for lunch at the same time, breakfast at the same time" (P4).* Having a set structure served to punctuate a long day, giving a sense of purpose; one mother described it as being "like a job" (P1). Some participants went on to reflect how being in the ICU for so long became "normal" – some families had never been home with their child or had spent more time in the ICU than at home. A number of staff used the term "institutionalised" to describe the familiarity that long-stay families have with the hospital environment and how the ICU works.

The process of moving from the acute phase, through a period of adjustment to a stage of normalisation was described in relation to three areas.

Knowledge

As a result of the length of time spent in the ICU, parents reported increased knowledge: the medical terminology used; the procedures and care given to their child; and the machines and

equipment present in the ICU. One mother reported: *"at the beginning within the first month I didn't have a clue; when I realised about the sats and blood gases and why they're doing this, it was so much easier because then I knew what they were doing..."* (P1). One mother described feeling more "empowered" as her knowledge increased: *"I was able to say '...Surely we can wait a few hours if his breathing is okay?'...It just meant that I felt more involved in the plan for getting him better"* (P25). Staff participants also reflected on the change in long-stay parents: *"they become more confident and they get to learn the medical terms. They adapt to the environment..."* (S11); *"the longer they're here the more expert they become"* (S13).

Workings of the ICU

Over time, inevitable shift-changes meant LSPs were cared for by a large number of staff. Increasing time spent in the ICU environment resulted in families adjusting to a constantly changing team of care providers. Throughout a long-stay, however, parents developed more familiarity with the environment and working of the ICU, such that their 'new normal' comprised knowing *"much more about the ICU course"* than staff did (S16). One father described his experience: *"sometimes I felt more on top of it than everyone else...I'd sat there day in day out...There were times when someone said, 'We might need to do this,' and I was, 'You did that yesterday'"* (P18). *Staff in the ICU*

Familiarity with staff enabled parents to distinguish between different nursing styles and most parents recalled favourite nurses in the ICU: *"I see lots of nurses, lots! Lots of nurses and from agencies and the difference-, you can see different work, different regimes, like how they're doing everything, how we check. It's really different"* (P8). This quote reflects the shift beyond parents adjusting to different staff within the ICU to them actively monitoring and evaluating their ways of working. This sense of 'knowing' that came with a long-stay in ICU was such that it impacted on parents' everyday thinking about who had been allocated to care for their child. As one father said,:

'Okay, it's a change of shift, who are we going to get...' By that time you knew pretty much all the staff, and it would be, like, 'Oh thank goodness,' or, 'Oh, my God, this is going to be a hell of a...'
(P18).

PARENT AND STAFF INTERFACE

Conflict

Some staff spoke about 'challenging' families – *"when parents are acting out maybe asking incessant questions or criticising what's being done at the bedside"* (S2) or try to *"have some control over how things happen for their child"* (S4). Staff participants also observed that long-stay parents may be more likely to have suffered a setback or error during their child's ICU journey and are perhaps more likely to experience frustration at staff and the hospital system. The "up and down" nature of their time in the ICU means that *"if any little thing goes wrong for them [long-stay parents] it has a big impact"* (S13), and as a consequence "conflict" may be more likely with parents of long-stay families. One staff participant suggested that increased knowledge and familiarity with the environment may mean that long-stay parents are more "critical". One father recalled being spoken to about his behavior when he gave "guidance" to the nurse: *"I remember once when I was told off...one of the consultants, took me into a room and said, 'You're stressed' ... some nurse had obviously reported...this was a few weeks in...I was just saying, 'Can you please do this?' or whatever. Maybe I'd got slightly irate because she was in distress, and this woman [nurse] wasn't helping"*
(P24).

Involvement in child's care

Being involved in caring for their child was discussed by both staff and parents as a key part of being in the ICU. One staff participant observed the difference between shorter-stay and long-stay parents: *"they're [shorter-stay parents] not too involved in the care of their child, it's only when*

they go up to the ward... for longer-term patients we try to get the parents involved in their care..." (S12). Parents greatly valued any opportunity to be involved in their child's care: *"every little thing that I was allowed to do for her meant so much to me"* (P23). Involvement was perceived by parents as facilitated by the nurses: *"They let us do little things that we could do, like feeding and cleaning his mouth"* (P21). One mother spoke about checking whether she could do things for her child: *"...every new nurse, I was going, 'Is it alright if I do his cares today? Is it alright if I moisturise his feet?"* (P25). Parents' involvement in their child's care was varied. For some parents it was unclear how involved they could be: *"I think we were scared in some ways of what we could or couldn't do. We were never really told..."* (P18). One mother described how her involvement was dependent upon which nurse was looking after her child: *"It was very much driven by the nurse, so there were some nurses who would let us do stuff and then some nurses who wouldn't"* (P23). Staff also recognised the importance of involving families in their child's care: *"it's the small things they can do that give them a little bit of independencegetting families involved normalises the experience."* (S9). Other staff suggested that there could be negative consequences of involving parents: *"Parents becoming involved in child's care can be helpful but it can also block your relationship with a patient which isn't helpful when they're not there"* (S5)

Individualised Care

It was important for parents to feel that care was tailored to their child's need, not necessarily doing things 'by the book'. One mother described her frustrations when nurses continued hourly observations despite her efforts to introduce a normal sleeping pattern: *"Some, I think not all nurses... maybe they don't understand how mum feels. They're just doing what is in the book..."* (P8). Continuity in nursing care helped to build familiarity: *"... the reason why she was amazing was because she kept getting [my child] and she kept asking for [my child].... so the more...you look after a child, obviously the more you're going to get to know that child...it just then works seamlessly"* (P23).

Long-stay parents viewed 'care' as more than just medical competency; "handling skills", regular suctioning, nappy changing and ensuring a clean and tidy bed space, became important for parents when their child was less acutely unwell. One mother described how she felt when she considered that her child's basic needs had not been met: *"I think in some respects if you don't need to be in ICU, you shouldn't be in ICU because you're not getting the best care necessarily...you know some days I'd come back and I'd be thinking...she had a one-on-one nurse just to find out that really she didn't, and her bed was sloppy and her gastrostomy was messy. There was blood on her bed"* (P6). It was evident that parents and staff may hold different views on care priorities: *"basic care is extremely important as well but the things that mum gets upset about may not be a big deal in the eyes of an intensive care nurse..."* (S1).

Transition

Parents recalled mixed emotions when it was time to leave the ICU. Although their child was well enough to go after many weeks' stay, the transition for some seemed "sudden" and "scary" as parents left the familiarity of the environment, the staff and their own routines. One mother whose child had been in the ICU for 12 weeks reported: *"we were leaving this routine that had become our normal... that was life and it was more than the life we'd known the three weeks of being parents"* (P3). One mother recalled feeling overwhelmed after leaving the ICU: *"the child is left with the parent who actually doesn't know what to do"* (P5). It was evident that the ward environment placed a greater emphasis on the parental role in providing care: *"your staff support has gone down, but what you're expected to do as a parent has gone up"* (S8).

Discussion

This paper presents findings from one of few studies that have explored the impact on parents of having a child in the ICU for a prolonged period. Every long-stay family is different; how parents cope when their child is admitted to ICU in a critical condition may be largely determined by how they manage and deal with stress and problems in general (6). Parents will take on different roles, some being more passive and others more proactive during their child's admission (2). Our findings indicate that some families will adapt and grow accustomed to being in the ICU, and others will become increasingly exhausted and frustrated; some will experience both at times. Given the unpredictable nature of their child's medical condition it is likely that their experience will change and vary throughout their time in the ICU. However, there are a number of elements that are more likely to occur during a long-stay, as illustrated by our model depicting the process by which parents adjust and become normalised to the ICU and the associated challenges that occur at the interface between parents and staff. Evidence from studies of parents who have a shorter stay in ICU suggest that there are areas of overlap with our model in terms of parents' wish for participation and involvement in their child's care, concerns about inconsistency of care and the importance of their relationships with staff (30). However, with the increased knowledge and familiarity that comes with a long stay, the nature of the emotional intensity experienced by parents changes from one of uncertainty (30) to a sense of knowing about the workings and environment of the ICU, what is happening to their child and what they want for their child.

Our findings support previous research suggesting that the physical aspects of the ICU and ICU-related procedures become less stressful for parents over time as they become more accustomed to being in the ICU. Meyer et al. (6) found that staff communication and behavior became more important in determining parental stress as their stay in the ICU lengthens. Indeed, as the numbers of staff looking after their child increased alongside their knowledge and familiarity, parents of LSPs became more attuned to individual nursing styles, developing 'favourite' nurses. When their child became less acutely unwell, basic and holistic care held greater importance for long-stay parents.

Parents in earlier studies consistently identified alteration in their role as they transition from being the parent of a well-child to the parent of a critically ill child as a tremendous stressor (11, 12). They value any opportunity to be involved in their child's care, finding it hugely beneficial to their coping (14, 16). Our data suggest that, as their confidence and familiarity with ICU increases, parents of LSPs are more likely to be involved in caring for their child in the ICU, in contrast to parents of children who have an average-length stay who are likely to become involved when their child leaves the ICU. However, our data suggest inconsistencies in how this increased parental involvement was facilitated by staff; this is of particular relevance to bedside nurses who are largely responsible for enabling involvement. How parents feel about being involved in their child's care should not be underestimated by staff. Of importance for practice is ensuring that where possible parents are encouraged and supported in being actively involved in the care of their child and that this happens as early as possible during a child's stay. Staff should negotiate parental participation directly with the parents and, where necessary, may find it useful to make suggestions on how they can be involved and give examples of what has worked with previous families (14).

Our findings build on previous research which suggests that conflict at the interface between parents and staff may be more common in the care of ICU patients who have a prolonged stay (26), who are likely to be more knowledgeable than their average-stay counterparts, ask more questions, expect to be involved in decisions regarding their child's care, and wish to participate in the delivery of care at the bedside (6). Of importance for practice is awareness of this potential difference and the need to build and maintain good communication with the parents as research suggests that breakdown in communication is a factor leading to conflict between the medical team and family (26). Long-stay parents may be more likely to consider themselves as equal members of the team providing care to the child and, where appropriate, opportunities for staff to involve parents in providing care, developing care plans and decision-making should be utilised.

Results from our study indicate that the majority of families made an adjustment to being in the ICU – becoming “normal” for many. The imposing technology and high levels of monitoring that

were initially overwhelming became reassuring and comforting over time. Although parents realised that a move to the ward meant an improvement in their child's health, for some the transition brought feelings of anxiety and distress. Anxieties around transfer are well documented in relation to average-stay parents (31-33). Supporting previous findings (34), over a prolonged period parents in our study became more accustomed to and dependent upon one-to-one nursing and therefore found the transition overwhelming. Staff should ensure that long-stay parents are fully informed and supported throughout transition.

There are some limitations of this study. Firstly, parents approached to take part were those known to specialist nurses who assisted with recruitment - it is possible that families opting into the study were those who had a better relationship with the nurses at the hospital. Only long-stay parents were interviewed and any comparison made to average-stay parents is based on the literature and views of staff.

Conclusion

Long-stay families in the ICU face a prolonged period of uncertainty about the outcome for their child. Despite differences between families, there are a number of shared experiences which serve to characterise a long-stay in the ICU. Long-stay families will become more familiar with the environment, more knowledgeable about their child's needs and more familiar with the staff looking after their child. The unpredictable nature of their child's condition and the length of stay may mean that families are susceptible to exhaustion and frustration. Our study provides greater understanding of the experience of long-stay parents in the ICU and should encourage awareness and reflection amongst staff about how they can support long-stay families.

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