The challenges of caring for long-stay patients in the Paediatric Intensive Care Unit

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Abstract

Background and Aims: When compared to shorter-stay patients, caring for long-stay patients (LSPs) in the Intensive Care Unit (ICU) entails a disproportionate burden for staff. Our objective was to gain a deeper understanding of the impact on staff of caring for children who have a prolonged stay on the Paediatric Intensive Care Unit (PICU).

Methods: Semi-structured interviews were conducted with 17 members of staff (7 psychosocial staff, 7 nurses, 3 consultants) working in the PICU, NICU or CICU (PICU will be used to encompass NICU, CICU and PICU for the remainder of the paper) at a Children's Tertiary Health Care Centre. Interviews were tape-recorded, transcribed and analysed using Framework Analysis.

Results: Staff reported both positive and challenging aspects of Caring for LSPs in the PICU. Five key areas relating to the challenges of caring for LSPs were identified: staff expectations about their work, characteristics of the patient group, the impact on staff and the wider unit and the availability of support. Staff views were often compounded by individual cases they had been involved with or had heard about which fell at either end of the spectrum of 'good' and 'bad'.

Conclusions: Whilst there are reported benefits associated with Caring for LSPs, there are a number of challenges reported that may have implications for staff and the wider unit. When caring for a particular sub-group of LSPs, staff may be more likely to experience negative impacts. A key priority for the PICU is to ensure that support mechanisms are timely, accessible and allow staff to explore their own reactions to their work.

Introduction

There are approximately 16000 admissions annually to paediatric intensive care units (PICU) in England and Wales (1), with a high patient turnover and an average stay of 2 days (2). Improvements in life-sustaining treatments have resulted in increasing numbers of children hospitalized for long periods of time in the PICU and whose care requires considerable resources. Whilst there is no consensus on what constitutes a long-stay in PICU, long-stay patients (LSPs) represent the minority (3-4). Much existing evidence regarding paediatric LSPs relates to mortality rates and quality-of-life indicators and, whilst there is a wealth of literature relating to the stresses and coping strategies of nurses in the PICU, relatively little is known about the impact of caring for children who have a prolonged stay in the PICU.

Nurses who come to the PICU are often attracted by the challenging and advanced technological nature of the work, as well as the opportunity to increase their knowledge and skills and make fast-paced decisions related to patient care (5-6). Similarly, physicians find the complex, fast-paced environment both challenging and interesting (7). When a child recovers from a life threatening event, nurses often feel a sense of accomplishment, however when cure is not possible, as is the case with some chronic PICU patients, "nurses may lose hope and feel that care is second best" (8). Nursing staff are the largest professional group in the PICU; they are particularly vulnerable to stress and burnout (9) and have little time to consider self-care (10). Whilst many critically ill children make progress in the PICU – which is fulfilling for the nurse – caring for the chronically ill child who does not recover can be emotionally draining (8).

Family-centred care (FCC) is at the core of Paediatric nursing. Evidence supports the integral role of families in a child's recovery and well-being. Care is planned around the whole family, with both the child and family considered recipients of care (11). Recent research has highlighted a number of challenges to implementation (11,12). A review of FCC in the PICU suggested that at the present time there is little evidence of improvement over the last 20 years which the author suggests could be due to insufficient time for the guideline to have a measurable impact (12).

When compared to shorter-stay patients, LSPs place a disproportionate burden on staff in terms of the related emotional stress and the challenges of decision making (13) and can result in withdrawal and loss of interest, burnout, job dissatisfaction and staff turnover (13, 8, 14). In light of these potential difficulties, our objective was to gain a deeper understanding of the impact on staff of caring for LSPs on the PICU, as part of a wider study exploring the implications of long-stay for staff and families. Understanding staff experiences of caring for LSPs will enable us to identify possible mechanisms for reducing adverse effects, potentially benefiting patient outcomes.

Materials and Methods

Participants

A purposive sampling frame, ensuring a mixed representative sample, was used to recruit medical, nursing and allied-health professionals working in 3 ICUs and adjoining wards in a tertiary Paediatric health care setting. Annual admissions to these units averaged over the 6 years was 1724. Lead clinicians were sent study information to share with their teams. Participants then contacted the research team directly if they were interested in taking part. Written informed consent was obtained from all participants prior to commencing interviews. To avoid identification of participants, direct quotes used to illustrate findings will be attributed to Staff Participant (SP).

Interviews

Interviews lasted 30-60 minutes and took place in quiet rooms across the hospital. Interviews were audio recorded and transcribed verbatim. A summary of the interview topics is provided below in Figure 1.

Figure 1. Interview Topic Summary

FIGURE 1

Data Analysis

Qualitative data were analysed using the Framework approach (15), which is recognised as being specifically appropriate for analysis of large amounts of qualitative data in a short timeframe. It is particularly suited to research involving multiple sources of data and is designed to involve a team of researchers in the analysis. The analytical process involves five distinct, though highly interconnected, 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 (16).

Results

Findings

Seventeen staff members participated in the study: three consultants, seven nursing staff and seven allied-health professionals. Four of the participants were male and thirteen were female. The majority of participants had been working in Paediatric critical care for at least two years; the range was between 9 months and 21 years. Data was collected over a nine month period. Data from an internal audit on PICU relating to length of stay and survival rates have been used where relevant to contextualise the findings.

All staff expressed their views on the needs of long-stay families and patients, and referred to the differences between care provided for LSPs and the 'average' ICU patient. Although some staff reported positive aspects of working with LSPs and acknowledged that "*it can be really good for PICU staff to get to know a child well...and really make a difference holistically"* (SP07), discussions focused more on difficulties experienced by staff. It was evident throughout interviews that staff reflected on specific LSPs they had provided care to; recent experiences on the unit had clearly had an impact on staff and consequently their responses.

Although participants worked in a variety of roles across the PICU, when they spoke about the impact of caring for LSPs, they largely spoke about the impact on the nursing staff, even if they themselves were not part of the nursing team. Quotes from several participants shed further light on this: "*the [designated] people who support the families are not there at the bedside...the doctors they come and go as well you know they don't have to be there 12 hours so I think the people who maybe miss out most are the people who are there the whole time*" (SP02); *"It's difficult, I think, because often what we hear is because of the shifts, staff find it really difficult to come away from the bedside, to have space to think about it"* (SP08)*; "Sometimes in those dire situations nurses feel like it's groundhog day with little support from the medical team. So nurses are just left to get on with it, basically, with the longer stay patients"* (SP13)**.** Five key areas were identified (see figure 2) which may account for *when* and *why* difficulties arise, the subsequent impact on staff and the wider unit, and current support for staff.

Figure 2. Proposed model of ways in which caring for long-stay patients can impact on staff

FIGURE 2

Characterisation of LSPs

Participants were asked what the term "long-stay" means to them. Participants drew upon their knowledge of local policies and practices, stating a specific number of weeks after which a patient is considered to be long-stay, and a number of unit processes reportedly "kick in". Most participants went on to describe their own definition which served to sub-categorise LSPs. For some this was a distinction between "long" and "extremely long" (see figure 3, quote 1), and sometimes involved consideration of the patient history and trajectory and whether they would soon be leaving the unit (see figure 3, quote 2).

Some described the changing profile of LSPs, with children being "sicker" and more "chronic" but stable: "*even though they're not deteriorating, there's no improvement*" (SP06). There was further concern that the development of life-sustaining treatments may lead to increasing numbers of LSPs (see figure 3, quote 3). Some staff saw particular LSPs as a more challenging group to care for (see figure 3, quote 4).

Figure 3. Selected quotations from staff perspectives on the meaning of 'long-stay'

FIGURE 3

Staff Expectations

Some staff expected certain things in relation to their role and the working environment of the PICU, including being able to receive training and develop and maintain their skills in the PICU, with an emphasis on their clinical skill set.

Some felt that skills are better developed when looking after a variety of patients, and there was a sense that nurses were 'entitled' to training opportunities – *"As a nurse you should have diversity looking after all different patients because that's what you're going for"* (SP06) – and when expectations were not met, in some cases, this was seen as "unfair". Some participants also discussed a potential skill mismatch between nurses who have been trained in the acute ICU environment and LSPs: *"Most nurses train to work in an acute setting - they're [LSPs] not seen as an acute patient"* (SP13).

In terms of the working environment, some indicated that they expected the work in PICU to be "fast-paced" with a "higher turnover" of patients and that this may attract a certain kind of individual to the unit: *"I wonder if there's something about the people…who choose to work in intensive care who are buying into short term work with families... and if that changes they're not used to that"* (SP04). For some staff there was also an expectation that they would make children better: *"the feeling is that children come in sick, over a period of time they get better and then they go out"* (SP14), which one participant termed the *"happy patient"* (SP03).

Impact on Staff

It was apparent that not all LSPs are perceived to cause difficulties for staff. LSPs who have a planned exit route or are slowly improving and responding to clinical care, may pose fewer challenges and offer some reward: *"I can think of LSPs...who have made spectacular recoveries after a very long course, and everybody feels very good about that, they've added something"* (SP15). The 'chronic' but stable LSPs with no planned or foreseeable exit route, may be more challenging in some cases, *"where no one feels that they've contributed to anybody's wellbeing"* (SP15).

Staff discussed several ways that caring for LSPs impacted them and their colleagues. Many participants reported a negative impact on clinical skill maintenance and development. One participant, speaking about a

patient who was on PICU for months, looked after by a handful of nurses, discussed how *"[this experience] completely deskilled them really, which isn't fair"* (SP06)

Some participants spoke about the additional challenges that supporting long-stay families may bring, particularly for bedside nurses: *"Supporting the family can be a huge emotional burden for the nurses at the bedside...because they're looking after somebody who's not making progress"* (SP02); *"the nurses are so set up for this kind of acute medical, kind of, crisis and everything they do is kind of around the limits of what they work within...a baby's blood pressure or a baby's heart rate should be within these limits... they've got so much to do in that moment just to keep a baby alive. I think all the, kind of, extra bit around parents and families is an extra stress...on their workload"* (SP08). Some participants suggested that staff and parents may hold different views on care priorities: *"what's important to parents are not important to intensive care nurses for example, the nurses here are trained for urgent care and not to say that basic care is not...because 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"* (SP01).

In some cases, caring for LSPs affected staff's sense of accomplishment and achievement, with staff feeling *"like they're not doing such a good job for them"* (SP04). The development of life-sustaining treatments led one participant to consider: *"Just because we can do something for a child, does that mean we always should?"* (SP08). It was evident that in some cases, moral distress and dilemmas may cause tension within the clinical team, with nurses sometimes frustrated by senior decision-making. As one participant recalls: "*we had one incident where the nursing team felt we should have pulled out a month before we did, so that child's life then dragged on for no purpose...when the nurses feel working there 24/7 knowing that child is suffering and they're inflicting pain...there are always these sorts of conflicts that come along with the longer-term children*" (SP13).

Some staff said it can be "demoralising" and "disheartening" when caring for some LSPs. Some staff, particularly nurses, described an "attachment" to LSPs and families which can lead to difficulties when a patient fails to improve or is "going through a rough patch". As one participant said: *"You do get a bit too attached...if you spend ten hours with someone for two months and you come home and you haven't quite left your work at work, you're still thinking are we really doing the right thing there"* (SP12). The death of a LSP may be particularly difficult as staff have developed a relationship with the patient and the family: *"the short term nature of ICU is quite protective of staff...because then they don't often get to know children and families very well...I think perhaps that helps them to cope with some sad outcomes at times…it's different to perhaps if you've known a family for four-five months and then sadly if the child were to die"* (SP04).

Impact on the Unit

Some participants described the wider impact on the PICU, including the effect of LSPs on the performance of the unit and the resulting issue of "bed blocking", as well as resource and cost implications. Staff found it difficult to consider that patients "who actually could do very well" have been turned away because of LSPs who may ultimately not benefit from care: *"we've turned away patients. If each patient stayed a week we could have had sixteen patients in that same bed space"* (SP12). Some participants referred to the pressure on the management team in trying to maintain "a good flow through the unit". One participant described a "big push at the moment" to have exit strategies in place for each patient, something which may not be possible for LSPs with no trajectory or prognosis to enable forward planning.

Some participants spoke about the overall composition of patients on the unit and the need to be "careful" about ensuring a large enough proportion of average-stay patients: *"if you have more than one long-term patient on the unit it's a huge proportion of your total patients when you've got 13 patients and two sometimes three are longer-term…"* (SP02). The need to find a balance was acknowledged.

Caring for LSPs was also seen to impact on staff morale, sickness and potentially staff turnover: *"If all your patients on the ward are not happy patients then it makes it really difficult to run the ward, The tone of the ward just goes down and the nursing staff get really depressed, people start going off sick…"* (SP03*).*

Although most participants discussed the widespread impact, there was also an indication from a number of participants that caring for LSPs may affect particular teams and cohorts of staff in the unit, for example junior nurses allocated to LSPs: *"it's gone to the bottom rung of the nurses within the team to look after her, primarily because they can't say no"* (SP03).

According to local unit policies, when a child becomes long-stay they are allocated a specific nursing team to ensure continuity for the family and patient. There was a suggestion that whilst this practice was beneficial for families, it may place a disproportionate burden on a small number of nurses. In the case of one LSP one participant described how *"some staff found that they were allocated there every single time and I think they found that hard being there every single time"* (SP11).

Several participants reflected on the lasting impact of caring for LSPs; regardless of the circumstances, said one, *"these families stay with you forever"* (SP02). As one consultant observed: "*You only need every two years one spectacularly difficult long-stay patient where everyone disagrees and the family have particularly strongly held belief that clashes with everybody else's. It just consumes huge amounts of everybody's time"* (SP15). This has implications for ensuring that staff have adequate strategies to cope effectively when caring for LSPs.

Staff support

Participants were asked what support was available to staff caring for LSPs. Although most described a number of support mechanisms within the unit, it was evident that participants were divided about how accessible they perceived support to be. Consultants and more senior members of the nursing team described the ways in which staff can access support (see figure 4, quote 5).

Some participants felt that despite the support mechanisms available, there were several associated issues particularly in relation to the nursing staff: the stigma attached to seeking help (see figure 4, quote 6); the difficulties of attending briefing and drop-in sessions whilst providing one-to-one nursing care; the challenge of returning to the ward in a highly emotional state (see figure 4, quote 7).

Another issue reported by some participants was the timeliness of support. One participant observed that support is largely provided when a patient dies but this fails to provide adequate support for staff caring for LSPs making little or no improvement (see figure 4, quote 8). Other participants felt that by the time they were able to speak to someone about how they were coping they had normally dealt with the issue themselves or it had passed. Some reported that speaking with peers helped them to cope.

Figure 4. Selected quotations from staff on current support mechanisms

FIGURE 4

Discussion

This paper presents findings from one of few studies that have explored the impact on staff and the PICU of caring for LSPs. Staff have different views on caring for LSPs: whilst some report the benefits and positive aspects, there are clearly a number of difficulties faced by staff which may have implications for those working in the PICU. Although we consulted a variety of health professionals working in the PICU, our findings suggest

that nursing staff may experience a greater impact of caring for LSPs than staff who do not work at the bedside for extensive periods. Understanding the impact is necessary to ensure that staff are supported and that the PICU operates efficiently.

Our findings suggest that, although local long-stay policies may serve a practical purpose in ensuring staff structures meet the needs of patients and families, it is clear that for staff the classification of LSPs is not limited to length of time on the ward. Staff have developed ways of defining this group of patients related to time, patient profile and trajectory. It is evident that "chronic", "extremely long-stay" patients may pose the greatest challenge; they confound staff expectations about working in PICU and staff can suffer distress in caring for patients who may never be well enough to leave PICU.

Our findings are supported by previous research which revealed that PICU staff are attracted to providing dynamic, fast-paced, acute care (5-6). Participants in our study often associated LSPs with slower-paced, more repetitive, holistic care, in contradiction to the expectations and beliefs they bring to the work. Many participants described the frustration of wanting to do a better job for LSPs and not achieving anything, as improvement was often absent. Our findings support previous research which revealed that staff, and particularly nurses, gain a sense of accomplishment from helping a child to recover from a life-threatening illness (8). Furthermore, when 'cure' is no longer possible, it can be difficult for care providers to feel as much of a sense of accomplishment. It is important for staff to be able to reframe their beliefs about cure being the most worthwhile goal in care provision. If staff are able to consider the wider benefits of providing basic and holistic care to the patient and family, they may be able to maintain a sense of accomplishment (8).

It was evident that there is an expectation that nurses coming to work in PICU will have the opportunity to train and develop their clinical skills. Staff perceived some LSPs as an obstacle in developing professionally; caring for them on a long-term basis was, in some cases, regarded as 'unfair' and in extreme cases led to deskilling. Although FCC views the family as equal contributors to care, it is evident that there may be problems in its implementation (11-12). In this study, some staff enjoyed being able to care for long term families, getting to know them and responding to their needs. It was also apparent that in some cases, parent and staff views on care provision may differ particularly in the case of LSPs when the parents have grown accustomed to the PICU environment, which may cause difficulties in realising the ideals of FCC. There is a need to emphasise the value of skills in providing holistic care and working with families, so that staff may be able to consider working with LSPs and families as an opportunity to refine these skills. There is an opportunity to learn from staff in PICU who enjoy working with LSPs, and their families who value holistic family-centred care, which may help to reframe any perceived loss of skills.

Although some participants who were not bedside nurses spoke positively about a variety of support systems available to staff, nurses reported a number of issues related to the availability and adequacy of these mechanisms. Firstly, staff were sometimes reluctant to ask for help, preferring to discuss issues with their peers and wait for things to pass. Some participants perceived a stigma attached to admitting that they were finding things difficult, and felt that difficulties associated with working in PICU were seen as part of the job. Secondly, bedside nurses found it difficult to be able to attend support sessions given the nature of their work. These findings are supported by research which suggests that the nature of the work, nursing staff on PICU provide one-to-one nursing, can mean that they have few chances to escape and reflect on their own reactions to the work (6). Thirdly, some participants felt that briefings were not always offered at the optimal time in a patient's journey. Whilst support is necessary when a patient dies, there are, as evidenced in this paper, difficulties faced when providing long-term care.

It is vital that bedside nurses have an outlet to consider their feelings and reactions to their work, as reactions to work stressors can have a powerful effect on subsequent reactions (17). Staff who experience success with a particular type of patient will be more likely to be optimistic when a similar patient next comes to the PICU,

whilst recent experiences of conflict and loss can have the opposite effect. All participants drew on previous experiences to present their views on LSPs, evidence that their views have been shaped by their experiences.

As research indicates, peer support groups have been shown to be a useful way for staff to express both negative and positive feelings about their work and can serve to develop positive attitudes and improve relationships between colleagues (8, 18). It is important to address the 'opt-in' nature of support, and the accessibility of support groups with regard to practical logistics. These groups should be led by a professional who can offer a balanced view, help staff to reframe their beliefs about their work and ensure that discussion amongst staff does not generate preconceptions about 'challenging' families and patients.

There are some limitations to this study. Firstly, whilst the findings are based on the views of hospital staff from a wide range of professional backgrounds, most of whom had considerable experience of working in the PICU setting, the views of less experienced and/or more junior staff may not have been adequately represented. Secondly, participants were self-selecting and therefore more highly motivated staff or those more able to express their views may have been overrepresented in the sample. Thirdly, participant views were evidently affected by previous experiences which staff drew upon during interviews. Qualitative interviews lend themselves to the relating of anecdotes, potentially placing greater emphasis on experiences at the extreme ends of the spectrum.

Conclusions

When caring for a particular sub-group of LSPs, staff may be more likely to experience distress, moral dilemmas, low morale and frustration at the perceived loss of their clinical expertise and inability to cure the patient. The PICU may experience increased sickness rates, reduced performance, and a higher turnover of staff. It is difficult to know how to meet the support needs of staff working in the busy environment of the PICU. To do so, staff need to be encouraged to recognise their own needs as well as offered guidance on being an effective support for families in the PICU. A priority for the PICU is to ensure that support mechanisms are timely, accessible and allow staff to explore their perceptions of patients and families, and reactions to their work. The opportunity to learn from staff who enjoy working with LSPs should be utilised as a way of encouraging staff to consider the benefits, not only for themselves but for the patient and their family.

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