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Original article

"Some were certainly better than others" – Bereaved parents' judgements of healthcare providers in the paediatric intensive care unit: 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

Objective: To explore bereaved parents' judgements of healthcare providers, as part of a larger study examining their perceptions of the death of a child in the paediatric intensive care unit.
Research methodology: Constructivist grounded theory.
Setting: Four Australian paediatric intensive care units.
Main outcome measures: Semi-structured, audio recorded interviews were undertaken with 26 bereaved parents 6–48 months after their child's death. Data were transcribed verbatim and analysed using open, focused and theoretical coding and the constant comparative method.
Findings: Bereaved parents judged healthcare providers as 'good' or 'poor' based on behaviours they exhibit. 'Good' behaviours were further subdivided by parents into four categories: 'Better than others', 'good', 'very good', and 'fantastic'. Common behaviours identified as 'good' included provision of practical assistance, facilitation of parental presence, and sharing of information. In contrast, the concept of 'poor' had no subdivision: all identified behaviours, including diminishing parental concern, mishandling hope, adopting an unprofessional demeanour, judging the child's worth, and mishandling communication, were equally detrimental.
Conclusions: Findings demonstrate that bereaved parents have clear opinions on what constitutes 'good' and 'poor' behaviours when their child is dying. These judgements provide clear examples for healthcare providers who provide end-of-life care, ensuring they provide high quality care.

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Implications for Clinical Practice

- Bereaved parents' judgements of healthcare staff provide landmarks for staff behaviours, attitudes, and interactions when a child is dying in the paediatric intensive care unit.
- Healthcare staff should endeavour to include the family in care, care for the parents (emotionally and practically), demonstrate respect for the child as a living person, appropriately share information, and provide all care competently and compassionately.
- Parents identified several behaviours healthcare staff should avoid, including providing false hope, removing parental hope, being too 'clinical', ignoring parental concerns, and communicating poorly.

Introduction

The hospitalisation of a sick child is a difficult experience for parents. Adding to the innate stress accompanying concern regarding their critically ill child, is the numerous interactions with a vast array of healthcare providers (HCP), from nurses and doctors through to allied health workers and non-clinical staff. Currently, no research explores the frequency of staff-parent interactions within the paediatric intensive care unit (PICU), but evidence from a general setting suggests that an average of 3.5 different people enter a paediatric patient's room each hour, 77% of whom are staff (Cohen et al., 2012). This may be even more prominent in the PICU, where staff are ever-present. Our experiences suggest that parents may be exposed to as many as 16 unique HCPs in any 24-hour period.

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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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Recent research has highlighted the significant impact interactions with staff members may have on parents' experiences in hospital, particularly when a child is dying (Butler et al., 2015a). Furthermore, these behaviours have been shown to have lasting impact on both the parents' memories of their child's death (Bright et al., 2009) and their subsequent grief (Meert et al., 2001). Despite a growing awareness of the impact of HCP behaviours, little is currently known about what parents themselves consider to be beneficial. Without this knowledge, HCPs have little guidance on how they should behave to minimise additional trauma for parents during such a difficult time.

This paper draws on findings from a larger study that explored the experiences of bereaved parents when a child dies in PICU. The findings presented here focus on bereaved parents' judgements of the quality of HCPs in the PICU environment.

Methods

Objectives

This paper aims to explore bereaved parents' judgements of healthcare providers in the PICU, as part of a larger study which aimed to explore their interactions with HCPs when their child died in PICU.

Methodology

Constructivist grounded theory was employed. Grounded theory focuses on social interaction and human behaviour, aiming to develop a theory grounded in the data (Charmaz, 2014). When paired with constructivism, grounded theory embraces the existence of multiple individual realities, ensuring that meaning is co-constructed between participants and the researcher to produce an interpretation capable of explaining these realities (Charmaz, 2014). The findings presented here, and the meanings and behaviours associated with each assigned judgement, represent this co-construction.

Ethical approval

Ethical approval was granted by four Human Research Ethics Committees (approval numbers 14276B; HREC/14/QRCH/355; HREC/16/WCHN/9; CF15/291-2015000145) and written informed consent was provided by all parents. Given the highly emotive nature of the interviews, participants were followed up one week after their interview, with social workers available for ongoing counselling if required. All data have been deidentified, and pseudonyms are used for all participants and their children.

Participants

Twenty-six parents (18 mothers and eight fathers), representing 18 children from four Australian PICUs, participated in the study. Characteristics of participant families and deceased children are summarised in Table 1. Parents were invited to participate based solely on the fact that they had a child die of an illness or accidental injury in one of the study PICUs 6–48 months prior to their participation. Both purposive and theoretical sampling techniques were used, with recruitment procedures including phone calls from social workers involved in routine bereavement follow-up care, and mailed letters to families who were not receiving follow-up. Further details of our recruitment methods have been published elsewhere (Butler et al., 2017a).

Setting

Participants were recruited from one of four hospitals across three Australian states. Hospital 1 is a mixed adult/paediatric hospital with a six-bed PICU attached to an adult ICU. It caters to approximately 600 admissions a year, and provides all critical care services to infants and children, with the exception of cardiac surgery, trauma care, and organ transplantation (Australian and New Zealand Paediatric Intensive Care Registry (ANZPICR), 2016). Hospital 2 offers a 36-bed PICU in a newly opened, 360-bed, tertiary paediatric hospital. The PICU provides all aspects of critical care to over 2000 children annually (ANZPICR, 2016). Hospital 3

Table 1
Characteristics of participating parents and their children.

Parent(s)[*]	Child's age	Cause of death	Type of death	Illness type	Past hospital experience	Length of stay	Time since death
Joshua and Evelyn	Infant	Single organ failure	Withdrawal	Chronic	Ward	9 days	1y 6 m
Emma	Infant	SIDS	Withdrawal	Acute	Nil	2 days	1y 4 m
Abigail	Infant	Single organ failure	Withdrawal	Chronic	NICU (direct PICU transfer)	8 weeks	1y 10 m
Vicki and Nate	Infant	SIDS	Withdrawal	Acute	Healthcare worker	6 days	2y 10 m
Layla	Infant	Neurological injury	Withdrawal	Chronic	NICU (direct PICU transfer)	Unclear	7 m
Sarah and Connor	Infant	SIDS	Withdrawal	Acute	Nil	3 days	2y
Zoe and Charlie	Infant	Single organ failure	Withdrawal	Acute	Nil	2 days	3y
Jessica	Infant	Single organ failure	Withdrawal	Chronic	Another PICU (direct transfer)	Unclear (1–2 weeks)	2y 6 m
Jasmine	Infant	Single organ failure	Withdrawal	Acute	Nil	5 days	1y 6 m
Lucy and Hudson	Toddler	Sepsis	Unsuccessful CPR	Acute	Nil	< 24 h	1y 1 m
Alice	Toddler	Accident/injury	Withdrawal	Acute	Nil	5 days	1y 2 m
Imogen	Toddler	Multi-organ dysfunction/sepsis	Withdrawal	Acute	NICU	Unclear (2–3 weeks)	4y
Erin	Toddler	Single organ failure	Withdrawal	Chronic	NICU	Unclear	3y 6 m
Hannah and Daniel	Teenager	Metabolic condition	Withdrawal	Chronic	Nil	5 days	8 m
Ryan and Zara	Teenager	Multi-organ dysfunction	Withdrawal	Acute	Healthcare worker	3 days	1y 8 m
Eva	Teenager	Anaphylaxis	Withdrawal	Acute	Nil	6 days	3y 8 m
Isabelle	Teenager	Cardiac arrest	Withdrawal	Acute	Healthcare worker	11 days	2y 10 m
Piper and Edward	Teenager	Neurological injury	Withdrawal	Chronic	Ward	3 weeks	3y

Infant: <1 year.
Toddler: 1–5 years.
Teenager: $\geq$13 years.
y – years, m – months.
[*] Pseudonym used.

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