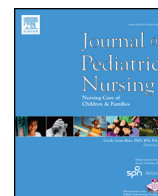




Contents lists available at ScienceDirect

Journal of Pediatric Nursing



Becoming a Team: The Nature of the Parent-Healthcare Provider Relationship when a Child is Dying in the Pediatric Intensive Care Unit

Ashleigh E. Butler^{a,b,*}, Helen Hall^a, Beverley Copnell^{a,1}

^a School of Nursing and Midwifery, Monash University, Clayton Campus, Wellington Road, Victoria 3800, Australia

^b Adult and Pediatric Intensive Care Unit, Monash Medical Centre, Monash Health, 246 Clayton Road, Clayton, Victoria 3168, Australia

ARTICLE INFO

Article history:

Received 20 September 2017

Revised 2 February 2018

Accepted 5 February 2018

Available online xxxx

Keywords:

Parent

Nurse

Relationship

Child death

Pediatric intensive care unit

Grounded theory

ABSTRACT

Purpose: To explore bereaved parents' perspectives of parent and staff roles in the pediatric intensive care unit when their child was dying, and their relationships with healthcare staff during this time.

Design and Methods: Constructivist grounded theory was used to undertake this study. Semi-structured interviews were conducted with 26 bereaved parents recruited from four Australian pediatric intensive care units. The constant comparative method, coupled with open, focused, and theoretical coding were used for data analysis.

Results: *Becoming a team* explores the changes that occurred to the parent-healthcare provider relationship when parents realized their child was dying and attempted to become part of their child's care team. When the focus of care changed from 'life-saving' to 'end-of-life', parents' perspectives and desires of their and the healthcare providers' roles changed. Parents' attempted to reconstruct their roles to match their changing perspectives, which may or may not have been successful, depending on their ability to successfully negotiate these roles with healthcare providers.

Conclusions: Findings offer insights into parental understandings of both the parental and healthcare provider roles for parents of dying children in intensive care, and the ways in which the parent-healthcare provider relationships can influence and be influenced by changes to these roles.

Practice Implications: Successful parent-healthcare provider relationships require an understanding of the parental and healthcare provider role from the parents' perspective. The meanings of the parental and healthcare provider roles should be explored with parents of dying children, and supported as much as possible to enable the development of a collaborative relationship.

© 2018 Elsevier Inc. All rights reserved.

Though the death of a child is a rare event within today's society, it remains one of the most devastating events in a parent's life. Despite studies suggesting that most families prefer their child die at home (Bluebond-Langner, Beecham, Candy, Langner, & Jones, 2013; Kassam, Skiadareisis, Alexander, & Wolfe, 2014; Vickers, Thompson, Collins, Childs, & Hain, 2007), the majority of children will still die in a hospital or hospice setting (Chang, MacLeod, & Drake, 2013; Pousset et al., 2010). The privacy of the home environment enables intimacy during this difficult time, however end-of-life care in a hospital context is usually associated with a plethora of unfamiliar people and activities entering the family's world. In addition to navigating the end of their child's life, parents may face a multitude of interactions and new relationships with healthcare providers. For many parents, their interactions with healthcare providers significantly influence their overall experiences

of their child's death (Butler, Hall, Willetts, & Copnell, 2015). These interactions can be positive, providing support and comfort, or can leave parents feeling excluded and uncared for both as their child is dying and during their early bereavement journey (Butler et al., 2015).

It is particularly important to understand these parent-healthcare provider interactions and relationships in the pediatric intensive care unit (PICU), as healthcare staff form a constant presence by the child's bed and, therefore, in the parents' journey. Though healthcare providers feature heavily in bereaved parents' experiences of their child's death in the PICU in the extant literature, they are most commonly discussed in relation to the support they provide (Macnab, Northway, Ryall, Scott, & Straw, 2003; McGraw et al., 2012; Meert, Briller, Myers Schim, Thurston, & Kabel, 2009; Meert, Briller, Schim, & Thurston, 2008; Meyer, Ritholz, Burns, & Truog, 2006; Michelson, Patel, Harber-Barker, Emanuel, & Frader, 2013; Yorke, 2011), their communication skills (Abib El Halal et al., 2013; Brooten et al., 2013; Macnab et al., 2003; Meert, Eggly, et al., 2008; Meert et al., 2009; Meert, Thurston, & Sarnaik, 2000; Meyer et al., 2006; Michelson et al., 2013; Yorke, 2011), their clinical skill and competence (Brooten et al., 2013; Yorke, 2011) or their overall

* Corresponding author at: P.O. Box 2742, Rowville, Victoria 3178, Australia.

E-mail address: Ashleigh.Butler@monash.edu (A.E. Butler).

¹ School of Nursing and Midwifery, La Trobe University, 185 Cooper St., Epping, Victoria 3076, Australia.

attitude and demeanor (Abib El Halal et al., 2013; Brooten et al., 2013; Macnab et al., 2003; McGraw et al., 2012; Meert et al., 2009; Meyer et al., 2006). Within this literature, discussions on the development or quality of parent-healthcare provider interactions and relationships, or the factors that influence and are influenced by these relationships, are largely absent.

In order to better understand these relationships, we explored bereaved parents' perspectives of their interactions with healthcare providers when their child died in the PICU. Findings from this study demonstrated that parent-healthcare provider relationships changed across three key stages of the parents' journey, termed *Welcoming expertise*, *Becoming a team*, and *Gradually disengaging*, which were influenced by changing parental needs and desires (Butler, Hall, & Copnell, 2018). This paper focuses on the second stage, *Becoming a team*, and explicates the parent-healthcare provider relationship in PICU when caring for a dying child.

Objectives

The aim of this paper is to describe the ways in which bereaved parents reconstructed the roles they desired for themselves and the PICU healthcare staff when they realized their child would die, and how their relationships with healthcare staff influenced these reconstructed roles.

Methods

Methodology

Constructivist grounded theory, outlined by Charmaz (2014), was employed for this study. Grounded theory is an inductive methodology which utilizes systematic data collection and analysis to develop a theory to explain patterns of human behavior and interaction within a social context (Charmaz, 2014; Engward, 2013; Higginbottom & Lauridsen, 2014). As a theoretical perspective, constructivism accepts the concept of multiple realities, allowing for acceptance of the different experiences and realities of each family involved in the study. In addition, data and their meaning are understood to be co-constructed between researcher and participants in a constructivist study, with the final theory offering one interpretation of many that could have been constructed to explain the participants' realities (Charmaz, 2014). The fact that this study offers one theory from many, which may have been constructed from the data is not considered to be a limitation, but rather reflects the very nature of constructivist grounded theory. The theory does not attempt to explain all the findings that might be possible, but rather offers one way to understand and predict the behaviors of the participants within the context of their experiences, that likely also have meaning and relevance for others in similar situations.

For these reasons, constructivist grounded theory was seen as an ideal platform to explore the research aim.

Participants

Bereaved parents were recruited from four PICUs across three states in Australia six to 48 months after their child's death. Recruitment methods varied depending on local ethical requirements but included a variety of opt in and opt out mailed letters from both the research team and a hospital-based research nurse, phone calls from social workers during routine bereavement follow-up, and advertisement at bereavement support groups. A more detailed discussion of our recruitment procedures can be viewed elsewhere (Butler, Hall, & Copnell, 2017). The research team did not have permission to access the total number of PICU deaths or the total number of families contacted about the study in hospitals 2, 3, and 4, thus the overall number of eligible families or the total number who declined participation in this study is unknown.

As is typical in grounded theory studies, purposive sampling was utilized for the first five participants, with theoretical sampling employed in a number of ways after initial concept development, including adding new sites, selecting families based on the child's age, illness history, or length of stay, and changing interview questions (Charmaz, 2014). A total of 26 bereaved parents from 18 families participated in the study: 10 individual mothers, and eight couples. Characteristics of participant parents and their children are provided in Table 1.

Data Collection

Parents took part in audio-recorded semi-structured interviews, at a time and location of their choice, common to grounded theory studies (Charmaz, 2014). Most parents chose to be interviewed in their own homes, though five parents requested phone interviews for privacy, comfort and logistical reasons. All parent couples preferred to be interviewed together, with each interview lasting between 90 and 150 min. Interviews began by asking parents to describe their family and how they came to be in the PICU with their child. In most interviews, parents then explored their PICU and bereavement journey sequentially, with probes used to explore developing concepts according to the process of theoretical sampling. Example interview questions are provided in Fig. 1. In addition, with permission, detailed notes were taken of conversations and comments made after the recorder was turned off. Interviews were conducted by A.B., a PICU nurse with prior qualitative interviewing experience. No member of the research team had a prior relationship with any participant.

Table 1
Characteristics of participating families.

Parent(s)	Characteristics
Joshua and Evelyn Emma	Infant, died after a planned withdrawal of medical therapy after 9 days in PICU. Cause of death: chronic congenital heart disease
Abigail	Infant, died after a planned withdrawal of medical therapy after 2 days in PICU. Cause of death: SIDS
Vicki and Nate	Infant, died after a planned withdrawal of therapy after 8 weeks in PICU. Cause of death: chronic congenital heart disease
Layla	Infant, died after a planned withdrawal of therapy after 6 days in PICU. Cause of death: SIDS
Sarah and Connor	Infant, died after a planned withdrawal of therapy after an unclear prolonged period of time in PICU. Cause of death: chronic neurological injury secondary to prematurity
Zoe and Charlie	Infant, died after a planned withdrawal of therapy after 3 days in PICU. Cause of death: SIDS
Jessica	Infant, died after a planned withdrawal of therapy after 2 days in PICU. Cause of death: acute liver failure
Jasmine	Infant, died after a planned withdrawal of therapy after 1–2 weeks in PICU. Cause of death: chronic congenital heart disease
Lucy and Hudson	Infant, died after a planned withdrawal of therapy after 5 days in PICU. Cause of death: acute liver failure
Imogen	Toddler, died after unsuccessful CPR less than 24 h after PICU admission. Cause of death: acute septic shock
Alice	Toddler, died after a planned withdrawal of therapy after 2–3 weeks in PICU. Cause of death: multiple organ dysfunction secondary to sepsis (underlying chronic illnesses)
Erin	Toddler, died after a planned withdrawal of therapy after 5 days in PICU. Cause of death: accident
Hannah and Daniel	Toddler, died after a planned withdrawal of therapy after an unclear prolonged period of time in PICU. Cause of death: chronic congenital heart disease
Ryan and Zara	Teenager, died after a planned withdrawal of therapy after 5 days in PICU. Cause of death: metabolic condition, possibly related to underlying chronic illness
Eva	Teenager, died after a planned withdrawal of therapy after 3 days in PICU. Cause of death: multiple organ dysfunction secondary to sepsis
Isabelle	Teenager, died after a planned withdrawal of therapy after 6 days in PICU. Cause of death: anaphylaxis
Piper and Edward	Teenager, died after a planned withdrawal of therapy after 11 days in PICU. Cause of death: cardiac arrest (underlying medical condition)
	Teenager, died after a planned withdrawal of therapy after 3 weeks in PICU. Cause of death: neurological injury (underlying neurological condition)

Download English Version:

<https://daneshyari.com/en/article/8573941>

Download Persian Version:

<https://daneshyari.com/article/8573941>

[Daneshyari.com](https://daneshyari.com)