



ORIGINAL ARTICLE

A qualitative interpretive study exploring parents' perception of the parental role in the paediatric intensive care unit

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KEYWORDS

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PICU;
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Parental role

Summary

Objectives: The purpose of this study was to explore parents' perception of the parental role in a tertiary care Canadian university affiliated hospital's paediatric intensive care unit (PICU).

Research methodology: A descriptive interpretive design was used with a purposive heterogeneous sample to reflect the range of children and parents normally admitted to the PICU. Semi-structured interviews were conducted with seven parents. Interview data were collected and analysed using the constant comparative method.

Findings: Three main themes emerged: (1) being present and participating in the child's care; (2) forming a partnership of trust with the PICU health care team; and (3) being informed of the child's progress and treatment plan as the person who "knows" the child best.

Conclusion: Enhanced understanding of the parental role in the PICU from the perspective of parents can help guide the development of strategies to more effectively support parents and promote parenting during this extremely stressful time.

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Introduction

Admission of a child to the paediatric intensive care unit (PICU) is an agonising experience for a parent. Fearful for their child's survival, and in a foreign and highly technical environment, parents must surrender their responsibility as protector and primary caregiver to healthcare profes-

sionals (Gillis and Rennick, 2006). Communication is more difficult as children are often sedated and intubated, and their appearance, emotions and behaviours are often changed. Parents may feel immobilised and experience a sense of helplessness in not knowing how to care for their child (Shudy et al., 2006).

Since the 1980s, parents have consistently identified alteration in their role as they transition from being parent of a well child to parent of a critically ill child as a tremendous stressor (Shudy et al., 2006). Despite this, few studies have used qualitative methodologies to better understand the nature of parental role alteration from the parent's

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Table 1 Interview guide.

Question	
1	Perhaps we can begin with your telling me a little bit about your experience in the PICU?
2	As a parent you are used to taking care of your child's needs in a certain way and you make sure he/she is well looked after. Yet, in the PICU, parents often say that so much of that changes. What has your experience been like?
3	How would you compare the way you were able to look after your child in the PICU with how you are used to looking after your child at home?
4	Can you describe for me what you were able to do or to say that was important to you in caring for your child in the PICU? What were you unable to do or say that you would have wanted to?
5	Many parents describe that the way their child looks and behaves in the PICU is quite different from how they normally look and behave and that this is quite stressful. Was this similar to your experience? How did this affect, if at all, the way you cared for your child?
6	Can you describe things that the health care team did that really helped or made it difficult for you to care for your child in the way you wanted to?
7	Is there anything else that the health care team could have done to support you in taking care of your child in the PICU?
8	Is there anything else you would like to add?

perspective. Since nurses are in a primary position to facilitate parenting, an enhanced understanding of parental role alteration from the parent's perspectives would help direct nursing interventions to support parenting in the PICU.

Literature review

A recent systematic review found the majority of studies on parenting the critically ill child focused on identifying parental stressors, needs and coping strategies (Shudy et al., 2006). In particular, Miles and Carter's (1982) Parental Stressor Scale: Paediatric Intensive Care, has been used extensively to quantify the prevalence of parental stressors. Whilst parental role alteration is repeatedly identified by parents as their greatest stressor, the measure provides little insight into the nature of that role alteration.

Other studies have used qualitative methodologies to explore families' and parents' PICU experiences. Roden (2005) found that parents understood their role to be what they would normally do at home; that is, "mothers do the mothering and nurses do the nursing." Findings emphasised the importance of nurses and parents clarifying their role expectations at the beginning of their relationship to facilitate communication and overall care of the family in the PICU. However, studies eliciting the desired roles and expectations of parents from their perspective remain scarce.

Snowdon and Gottlieb (1989) identified six types of parental roles in the PICU: vigilant parent, nurturer-comforter, medical parent, caregiver, entertainer and protector. This study contained an observational component that facilitated the identification of situational factors that may have contributed to altering the parenting role, including procedures at the bedside and the presence of family and friends.

Facilitators and barriers to parenting in the PICU have also been identified. Noyes' (1999) found the parental role was influenced by factors external to the parent-child subsystem, such as events preceding the PICU admission and the parents' family support network. Mu et al. (1997) found parents' perceptions of disempowerment and loss of the

parental role led them to expand their family's boundary and build shared patterns of caregiving interactions with the PICU nurses. Tomlinson et al. (1999) reported that parents' responses to surrendering their primary caregiving role in the PICU were not only affected by how nurses supplemented their role, but by how effectively nurses aided them in retaining their role as a parent.

Whilst these studies highlight the importance of intervening to help parents establish their role in the PICU, our understanding of parents' expectations and perceptions remains limited. This knowledge would allow clinicians to work with parents more effectively and support their essential contributions to their child's care.

The purpose of this study was to gain an in-depth understanding of parents' perception of the parental role when they have a critically ill child in the PICU. The research questions were: (1) what are parents' perceptions of their role in the PICU? (2) How do parents perceive their role to have been altered in the PICU? (3) What can nurses do to facilitate parenting in the PICU?

Methods

Design

A qualitative interpretive design was used to capture the contextual and unique nature of each parent's experience, whilst elucidating the shared realities of similar health-illness experiences within the PICU (Sandelowski, 2000; Thorne et al., 1997).

Sample

Children are admitted to the PICU with a wide range of medical diagnoses, ranging in age from infancy to 17 years; therefore, purposive sampling was used to ensure participants would reflect this heterogeneous group. Parents were included who spoke English, and whose child was being prepared for PICU discharge. Parents of children admitted for suspected abuse were excluded.

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