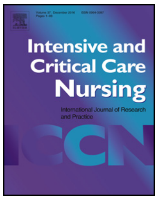
Intensive and Critical Care Nursing xxx (2017) xxx–xxx

Contents lists available at ScienceDirect

Intensive and Critical Care Nursing

journal homepage: www.elsevier.com/iccn



Nurses' perceptions of caring for parents of children with chronic medical complexity in the pediatric intensive care unit☆

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ARTICLE INFO

Article history:
Received 5 September 2016
Accepted 6 January 2017

Keywords:
Children with medical complexity
Pediatric intensive care unit
PICU
Nurse
Nurse-parent partnership
Patient and family centred care

ABSTRACT

Objectives: The aim of this study was to explore nurses' perceptions of caring for parents of children with medical complexity [CMC] in the pediatric intensive care unit [PICU].

Research methodology: An interpretive descriptive design was used to explore nurses' perceptions of caring for parents of CMC in the PICU. Semi-structured interviews were conducted with ten nurses. Interview data were collected and analyzed using qualitative inductive content analysis.

Findings: Nurses revealed that their experiences of caring for parents of CMC evolved over time as they learned to tailor a caregiving partnership based on trust. Although various circumstances could challenge this partnership, nurses strove to maintain and nurture it through self-reflection and optimal communication. Three themes were identified in the data that captured PICU nurses' perceptions: (i) "Thrown to the wolves": Adjusting to a new caregiving role; (ii) "Getting to know each other": Merging caregiving roles; (iii) "Keeping connected": Working to preserve the partnership.

Conclusions: Findings shed new light on the importance of a trusting nurse-parent partnership in caring for parents of CMC in the PICU. Results will be used to develop strategies to enhance this partnership, with the goal of supporting parents and staff in their caregiving roles.

Implications for clinical practice

- Implementing educational sessions for PICU nurses regarding the population of CMC and their families may facilitate the transition of nurses into the unique caregiving role of caring for parents of CMC.
- Making time to discuss mutual expectations with parents of CMC, while demonstrating flexibility and respect for parents' preferred level of involvement in their child's caretaking routine may empower parents of CMC and foster open communication, crucial in establishing a trusting relationship.
- Engaging in an open and transparent dialogue with parents of CMC, especially when facing ethically-difficult situations and when the child transitions to a more acute state, may serve to enhance the partnership with parents of CMC in these challenging moments.

☆ We would like to thank Dr. Antonia Arnaert for her ongoing support and guidance throughout the development of this study. We would also like to acknowledge the nurses in the PICU who were so generous with their time and in lending their knowledge on this important topic.

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[1] Dr. Rennick is a Fonds de Recherche du Québec-Santé (FRQ-S) Clinical Research Scholar, and a member of the Research Institute of the McGill University Health Centre, which is supported in part by the FRQ-S. This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

http://dx.doi.org/10.1016/j.iccn.2017.01.010
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Introduction

Dramatic advances in neonatal and critical care have allowed medically fragile children to survive (Burns et al., 2010). Medical equipment and technological advances, such as ventilator support, feeding tubes, total parenteral nutrition and transplantation, have successfully prolonged the lives of children with life-threatening conditions, creating a new generation of long-term survivors of childhood-onset diseases (Cohen et al., 2011, Cohen and Patel, 2014). These children experience lifelong comorbidities that are associated with high mortality. Children with medical complexity [CMC] undergo frequent re-hospitalizations, typically in the pediatric intensive care unit [PICU] where they are among a population of children with chronic health conditions that accounts for 45% of all unscheduled PICU admissions (Dosa et al., 2001). Many of these children have systemic health problems, including neurodevelopmental disabilities, gastrointestinal illnesses, pulmonary complications, musculoskeletal abnormalities and nutritional deficits (Burns et al., 2010). As a result, they require sophisticated medical and technological interventions in the hospital and in the home, where parents are expected to develop expertise in providing advanced medical care (Srivastava et al., 2005). Consequently, parents' critical position as experts in their child's care makes them unique in the PICU, where nurses are typically the expert care providers at the bedside (Graham et al., 2009). These parents' unique circumstances have been postulated to affect how health professionals care for them (Graham et al., 2009). In order to foster collaborative care in the PICU, it is important to understand how health professionals perceive caring for and partnering with parents of CMC. Nurses, who provide complex care while building important and trusting relationships with parents, are well positioned to describe this partnership (Meade et al., 2012).

Two studies examined the perceptions of parents of CMC when interacting with hospital staff. In a qualitative descriptive study, Hagvall et al. (2014) explored the needs of nine parents of CMC and their perceptions of nursing staff attitudes on an acute care ward in Sweden. These parents described feeling misunderstood and lacking support from the staff in meeting their child's basic care needs, such as toileting and eating, despite expressing willingness to be involved in their child's complex medical care. Unbeknownst to the parents, nurses expected them to independently fulfill these needs. These findings demonstrate that good communication and parent-staff partnerships are crucial in caring for parents of CMC in the hospital.

Within the PICU setting, Graham et al. (2009) conducted a qualitative descriptive study in which parents of eight children with severe antecedent disabilities were interviewed to assess their perspectives and needs regarding caring for their critically ill children. Parents identified the need for outstanding communication within the parent-professional relationship and the importance of recognizing the child's and parent's uniqueness. The difficulty that health care professionals encountered in understanding parents' particular circumstances was postulated to affect how they cared for and partnered with them. For instance, parents perceived that because PICU nurses did not know their child's baseline condition, their own knowledge of their child could have been a helpful resource. While this study highlighted the importance of partnership and care tailored to parent-caregivers of CMC in the PICU, nurses' perspectives of caring for these parents were not explored.

Meade et al. (2012) quantified the extent to which PICU nurses ($n = 105$) and respiratory therapists ($n = 50$) experienced distress when caring for children with complex medical and developmental disabilities. Through an online scenario-based survey, participants scored their level of distress with respect to statements assessing moral distress, mismatched expectations (between the health care provider's expectations and their experiences in practice when caring for CMC), and job dissatisfaction. Findings suggested that staff were most distressed by mismatched expectations, followed by job dissatisfaction and moral distress. This study did not include a comparison group, and while the authors hypothesized that higher levels of distress may interfere with nurses' ability to deliver care to CMC, this was not explored.

A qualitative study using grounded theory explored best practices and barriers related to interactions between parents of CMC ($n = 7$) and nurses ($n = 12$) in the PICU of a large urban hospital in the United States (Baird et al., 2015). The study revealed that some explicit rules in the PICU, including those relating to visitation, food, isolation precaution measures, and personal care needs, were often overlooked by parents and became a burden for nurses who believed they had to enforce them. Furthermore, nurses expected parents to understand the unit's implicit rules, such as knowing the routines, understanding that the nurses' focus of care was the child, and recognizing the expertise of the nurse. These rules were never discussed, creating confusion for parents. A mismatch between nurses' and parents' expectations also led to frustration on the part of the nursing staff, ultimately undermining optimal relationship development with parent-caregivers. This study highlighted some of the challenges nurses face in interacting with parents of CMC within the context of the PICU; however, further research is needed to understand nurses' perceptions of caring for and partnering with these parents.

Research regarding parents' and nurses' experiences of caring for CMC in the PICU setting is limited. Although it has been suggested that these parents' unique expertise in providing highly sophisticated care to their children may affect how nurses care for them, nurses' perceptions have not yet been explored.

Aim

The aim of this study was to explore nurses' perceptions of caring for parents of CMC in the PICU.

Methods

Design

An interpretive descriptive design was used to facilitate the discovery of associations, relationships, and patterns through an exploration of nurses' experiences (Thorne et al., 2004; Thorne, 2008). The investigators explored both the individual and contextual nature of nurses' perceptions, highlighting the similarities and differences in nurses' experiences of caring for these parents in the PICU.

Ethical approval

Prior to conducting the study, ethical approval was obtained from the Research Ethics Board of the hospital where the study took place.

Setting and participants

The study took place in a 19-bed PICU in a university-affiliated pediatric hospital. Purposive sampling was used to capture nurses' diverse perceptions of caring for parents of CMC in the PICU (Thorne et al., 2004). Study participants were selected from a pool of 70 nurses whose PICU work experience ranged from 2 to 34 years. The distribution of nurses according to years of PICU experience was as follows: 13% had 2–5 years, 28% had 6–10 years, 36% had 11–20 years, and 23% had more than 20 years (data provided by the PICU Nurse Manager). Nurses spoke English and/or French, and agreed to

Please cite this article in press as: Denis-Larocque, G., et al., Nurses' perceptions of caring for parents of children with chronic medical complexity in the pediatric intensive care unit. Intensive Crit Care Nurs (2017), http://dx.doi.org/10.1016/j.iccn.2017.01.010