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# Parents' Experience of the Transition with their Child from a Pediatric Intensive Care Unit (PICU) to the Hospital Ward: Searching for Comfort Across Transitions



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Parents of children in pediatric intensive care units (PICUs) have many needs and stressors, but research has yet to examine their experience of their child's transfer from PICU to the hospital ward. Ten parents were interviewed following transfer from PICU to a hospital ward at a children's hospital in Canada. Parents' experience involved a search for comfort through transitions. The themes were: 'being a parent with a critically ill child is exhausting', 'being kept in the know', 'feeling supported by others', and 'being transferred'. Findings from this study can help nurses and health professionals working with parents during transitions.

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THE PEDIATRIC INTENSIVE care unit (PICU) has been described as a stressful place for patients and family members due to the sudden, unexpected, and lifethreatening illness experience, and uncertainty regarding prognosis (Keogh, 2001). Once the child no longer requires critical care, he or she is transferred from the PICU to the hospital ward. A transition occurs when change is linked with experienced time (Meleis, 2007) and the movement from one setting to another can be referred to as a care transition (Geary & Schumacher, 2012). Thus, for the purposes of this study, the transfer of a child from the PICU to the general ward is considered a transition and the terms transition and transfer are used interchangeably. Nurses need to be cognizant that the transition from PICU to the ward can be a challenging experience for parents.

# Background and Literature Review

Many studies (Carnevale, 1990; Colville et al., 2009; Dampier, Campbell, & Watson, 2002; Heuer, 1993; Jee et al., 2012; LaMontagne & Pawlak, 1990) have examined parents' needs, stressors, and coping strategies in the PICU. Many authors have suggested that one of the most common needs for parents in PICU was the need for information (Aldridge, 2005; Carnevale, 1990; Colville et al., 2009; & Noyes, 1998). Parents also needed to be close to their child, which Colville et al. and Jee et al. called 'proximity to the child'. Parental stress in the PICU could stem from the environment related to lights, noise, and activity (Carnevale, 1990), from irregular and inconsistent information (Colville et al., 2009), or from a loss of parental role (Carnevale, 1990; Carter & Miles, 1989; Colville et al., 2009; Jee et al., 2012; Noyes, 1998). Parents used various coping strategies when their child

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was in the PICU. These included staying at the bedside for long periods to seek information (Jee et al., 2012), wanting a place to stay or rest near the child (Jee et al., 2012; Molter, 1979), and seeking assurance that they would be informed about changes in the condition of their child (Latour et al., 2011; Molter, 1979).

When children are moved from the PICU to the hospital ward, they and their parents undergo a physical transition from one place to another. During this transition, parents of PICU patients can experience transfer anxiety and uncertainty related to a loss of relationships developed during the crisis, not knowing what to expect on the new unit, changes in the nurse to patient ratio, and the decreased intensity of nursing observations (Ridling, Hoffman, & Desgkerm, 2006).

Both qualitative and quantitative methods have been used in studies examining parents and the transition of their child from PICU to a hospital ward. For example, quantitative studies evaluated parents' needs before transfer (Linton, Grant, & Pellegrini, 2008) and parent satisfaction with PICU (Haines & Childs, 2005). Some of the interventions parents found helpful were a discharge brochure or letter (Bouve, Rozmus, & Giordano, 1999; Linton et al., 2008), a transfer protocol (VanWaning, Kleiber, & Freyenberger, 2005), and a liaison nurse from the PICU who followed up with discharged patients and provided information, education, and support during the transition (Caffin, Linton, & Pellegrini, 2006).

There were two qualitative studies exploring parents' experiences of transition. Keogh (2001) found the transfer for parents from PICU was seen as a crisis, eliciting distress similar to that caused by the admission. Colville et al. (2009) found that parents knew the child was ready to go but found themselves unprepared, found the transition stressful, and reported that the transfer renewed their anxiety about the child's safety. Additionally, parents found the transition to and from the PICU were the most stressful periods of the hospital admission (Colville et al., 2009). Some parents had post-traumatic stress symptoms and retained vivid memories of the PICU when interviewed at 8 months after discharge (Colville et al., 2009).

While research has been conducted examining parents and the transition from the PICU, there were some limitations that make it difficult to draw conclusions about parents' experience. Namely, that previous research has not looked at transitions exclusively and/or the studies were retrospective in nature with data collection occurring up to 8 months following PICU discharge. In addition, authors agreed that a qualitative approach would be best to understand the experience of the transition for parents (Dampier et al., 2002; Keogh, 2001; Noyes, 1998). Consequently, a singular focus on the parents' experience of the transition, as it is actually lived, from the PICU to the hospital ward utilizing qualitative methodology, specifically phenomenology, was required to more fully understand this experience.

#### **Purpose**

The purpose of this study was to describe the lived experience for parents when their child was transferred from the PICU to the hospital ward. The objectives were to describe: (1) the parents' perspective of the transfer process, (2) supports and challenges during hospitalization and the transfer, (3) information received during the hospitalization, and (4) the differences between the PICU and the hospital ward.

## Study Design/Methodology

The research design that captures an understanding of the lived experience for parents of the transition from the PICU to the hospital ward is the hermeneutic phenomenologic method. This method, also called interpretive phenomenology, explores the lived structures and meaning of human phenomena to people who have experienced it, primarily through open-ended interviews followed by analysis and phenomenological writing (VanManen, 1990). The ultimate goal of this type of methodology is to develop an interpretive description of the phenomenon using participants' own voices (VanManen, 1990).

### Sample and Sampling

At the outset, a purposive sample of ten parent participants was the aim for the study, since most phenomenologic studies have six to ten participants (Polit & Beck, 2008). Inclusion criteria for parents were: (1) age greater than 18 years, (2) English speaking, (3) the parent (biological mother and/or father, or legal guardian) of a child being transferred from the PICU to the hospital ward, and (4) the transfer had occurred less than 48 hours prior to the interview. The criteria for the child were: (a) no more than 18 years of age, and (b) admitted to the PICU for more than 24 hours for an acute, lifethreatening illness, requiring ventilator or hemodynamic support. Exclusion criteria included: (1) the parents of a child readmitted to the PICU on the same hospital admission and (2) involvement in a Child & Family Services case (i.e. admitted for suspicions of child abuse or neglect). All efforts were made to include both mothers and fathers, or both parents of a child.

Reading and re-reading of the interview transcripts occurred as data collection was ongoing. Interviews continued until the thesis committee, which was composed of three nurses who together were experts in critical care, qualitative methodology, family-centered care, and pediatrics, agreed that by the tenth interview rich descriptions of the phenomenon had been achieved, with no new information revealed.

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