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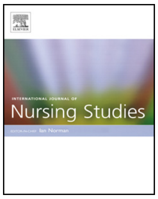

The lived experience of parents of children admitted to the pediatric intensive care unit in Lebanon

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ABSTRACT

Background: Family caregivers have a significant responsibility in the care of their child in the Pediatric Intensive Care Unit (PICU). Parents staying with their child in the PICU have particular needs that should be acknowledged and responded to by clinicians. Several studies have been conducted in the USA and Europe to try to understand the experience of family caregivers of children admitted to the Pediatric Intensive Care Unit. There are no such studies in Lebanon or the Middle East where the culture and support systems differ from other countries.
Objective: To understand the lived experience of Lebanese parents of children admitted to the PICU in a tertiary hospital in Beirut.
Design: Phenomenological study.
Methods: The study followed purposeful sampling in which 10 parents (mother or father) of children admitted to PICU were interviewed. Data were analyzed following the hermeneutical process as described by Diekelmann and Ironside (1998).
Results: A constitutive pattern "*Journey into the unknown*" which constitutes an overarching theme and four major themes with subthemes emerged from the data. These were: *We are human beings with dignity* "; "*looking for a healthier environment*"; *Dependence on God* and "*The need to be in the loop*" reveal the parents' journey into the unknown.
Conclusion: This qualitative study adds to the knowledge that would help health care workers understand the experience of Lebanese parents with a child in PICU and to highlight the significance of this experience to them. The findings could be used to inform the development of a PICU parental satisfaction instrument for the sample group.

What is already known about the topic?

- Communication problems in PICU have been reported between parents and health care workers.
- Psychological support is highlighted as an important need for parents in PICU.
- Parents want to be kept informed while their child is in PICU.

What this paper adds

- Participants of this study described the whole experience as a journey into the unknown.
- Participants of this study reported that the use of English language by the staff while talking with them was a major concern and a hindering factor for proper communication.

1. Introduction

The admission of an infant or child to the Pediatric Intensive Care Unit (PICU) is a difficult experience for both the child and parents/caregivers (Board and Ryan-Wenger,

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2002; Diaz-Caneja et al., 2005; Noyes, 1999) with previous research showing the experience to be more stressful than any general hospital admission (Board and Ryan-Wenger, 2002; Diaz-Caneja et al., 2005; Youngblut et al., 2005). When a child is admitted to PICU, parents often face a spectrum of psychological adversities, financial, and quality of life compromises that extend to affect the family as a whole (Board and Ryan-Wenger, 2002, 2003; Colville et al., 2009). This issue led other researchers to describe the admission of a child to the PICU as a "family event" (Harbaugh et al., 2004).

During the "family event" there is enormous psychological burden inflicted on the parents which is apparent by experiencing anxiety (Needle et al., 2009), grief (Colville et al., 2009), acute stress (Balluffi et al., 2004; Diaz-Caneja et al., 2005), and post-traumatic stress disorder lasting after the experience (Bronner et al., 2008; Colville and Gracey, 2006; Ward-Begnoche, 2007). Previous studies found that the major stressors for parents of children being cared for in a PICU include the child's illness severity (Diaz-Caneja et al., 2005; Nizam and Norzilla, 2001), need for mechanical ventilation (Needle et al., 2009), their child's appearance during the admission (Diaz-Caneja et al., 2005), concerns about the child's future (Balluffi et al., 2004), sights and sounds in the PICU (Board and Ryan-Wenger, 2002, 2003; Diaz-Caneja et al., 2005; Macdonald et al., 2012), procedures done to the child (Board and Ryan-Wenger, 2002, 2003), inability to be present with the child (Diaz-Caneja et al., 2005), their displacement from familial roles (Nizam and Norzilla, 2001), feeling of uncertainty and helplessness (Jee et al., 2012). The needs of parents ranged from physical space to personal support and communication (Hayakawa et al., 2009; Meert et al., 2008; Smith et al., 2007). In addition, families have different support systems or means that they use to cope with such a crisis.

Previous research showed these to include faith, solidarity, spirituality, and social network among others (Hayakawa et al., 2009, 2010; Robinson et al., 2006). The ultimate aim of healthcare professionals in caring for families in such situations was to provide holistic, family-centered care, which attends to their needs and facilitate their experience during their child's illness (Hall, 2005b; Noyes, 1999). However, health care providers cannot accurately know the feelings and needs of these parents (Needle et al., 2009; Noyes, 1999; Wills and Wills, 2009) and the meaning this event carries for them (Noyes, 1999). It has been shown that parents often want to discuss or give feedback about their PICU experience (Agarwal et al., 2008; Colville and Gracey, 2006; Wills and Wills, 2009).

Qualitative studies have been performed in some centers in USA (De Lemos et al., 2010; Johnson et al., 1995; Meert et al., 2008; Meyer et al., 1998; Needle et al., 2009), Canada (Aimes et al., 2011; Carnevale et al., 2007; Kirschbaum, 1990), South America (Hayakawa et al., 2009), Europe (Colville et al., 2009; Colville and Gracey, 2006; Diaz-Caneja et al., 2005; Hall, 2005b; Latour et al., 2011b; Noyes, 1999; Spitz-Koberich et al., 2010), Australia (Haines et al., 1995; Maxton, 2008) on different aspects of the parents' PICU experience and revealed that trust and communication, caring attitude of the health care team, need for information and involvement in care, presence with the child, as well as coordination for the continuity of care emerged as issues of concern to these parents in varying degrees. In the study by Hall (2005) on Danish PICU parents, it was shown that these parents were insecure and anxious for their child's condition but at the same time attentive and alert to events going on around them (Hall, 2005b). German researchers Spitz-Koberich et al. (2010) in a study assessing parental expectations from the team of PICU revealed the need for parents to be involved, informed and to experience continuity of care when their child was in the PICU. Parents expressed the desire for continuous medical support. Other ethnic and cultural groups can have differing needs, perceptions, and expectations (Hall, 2005a; Spitz-Koberich et al., 2010; Tseng and Verklan, 2008).

However, no studies to date have addressed the parental experience of PICU stay in Lebanon or even in the Middle East. Therefore the aim of this study is to fill this gap by exploring the lived experience of Lebanese parents who have a child admitted to the PICU. Eventually the research question is: What is the lived experience of parents of children admitted to the PICU in Lebanon? It is worth noting that in Lebanon the family as represented by close relatives (mother, father, sisters, grandparents, cousins) is a major support system especially during hospitalization of a child.

2. Methods

2.1. Design

This qualitative study followed the Heideggerian interpretive phenomenological approach as described by Diekelmann and Ironside (1998). A Heideggerian hermeneutical study uses an interpretive phenomenological approach to uncover common meanings in narratives and to understand the context of a situation. By interpreting narratives describing the personal experiences of Lebanese family caregivers of a child admitted to PICU, the researchers gained insight into the feelings of these parents and the meaning assigned to these feelings in order to obtain a beginning understanding of their lived experience.

2.2. Ethical considerations

Approvals for studying human participants were obtained before beginning the study from the Institutional Review Board (IRB) of the American University of Beirut and the American University of Beirut Medical Center. Established procedures for protecting confidentiality were strictly followed. All participants read and signed a consent form and received a pseudonym to maintain anonymity. At the first meeting and at all subsequent interactions, the participant was reminded that his/her participation was voluntary and that at any time he/she could decline or withdraw from the study without any obligation. None of the participants opted to withdraw from the study.

Each interview was coded so that only the study investigators had knowledge of the individuals who