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Family Stress in Pediatric Critical Care

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ABSTRACT

This mixed methods study explored stress in families whose children were hospitalized in the pediatric intensive care unit (PICU) for more than one week. The study aim was to describe sources of stress for families whose children require extended hospitalization in the PICU. Data collection included semi-structured interviews and completion of the Family Inventory of Life Events and Family System Stressor Strength Inventory. Themes reported in this paper are separation, not knowing, and the child's illness and distress. Additional research is needed to validate these findings in families of other cultures and structures, and in other PICUs.

Background

Families of critically ill children experience significant disruption of their "normal" lives – both during hospitalization and in the weeks, months, and years that follow (Board & Ryan-Wenger, 2002; Carnevale, 1999; Harbaugh, Tomlinson, & Kirschbaum, 1996; Johnson et al., 1995). As new life-sustaining technology has become available to improve clinical outcomes, the number of children requiring prolonged hospitalization in the pediatric intensive care unit (PICU) has increased (Alkandari et al., 2011; Graf, Montagnino, Hueckel, & McPherson, 2008; Staveski, Avery, Rosenthal, Roth, & Wright, 2011; Typpo, Petersen, Hallman, Markovitz, & Mariscalco, 2009). While the median length of stay (LOS) in the units where this research was conducted was 1.8 days during the five years leading up to and including the year of the study, the percentage of children with PICU LOS greater than fourteen days had increased from 5.7% to 7.3% and 120 children (2.5% of all children admitted) had been treated in the PICU for more than 30 days. In addition to efforts to improve clinical outcomes for this growing population of patients, we must seek ways to assess and improve family outcomes, since little is known about the stress families experience as hospitalization becomes prolonged.

Family stress has been defined as "a systemic response of the family as a unit…often related to loss or anticipated loss manifest as change in family function," such as family disorganization, family conflict, and role dysfunction, "all of which can be magnified by ambiguity and uncertainty that accompanies critical and emergent health changes" (Tomlinson, Peden-McAlpine, & Sherman, 2012, p. 706). Studies of family stress in PICU have identified a number of stress sources including uncertainty related to the environment, caregiver roles (Turner, Tomlinson, & Harbaugh, 1990), and the child's condition (Mu & Tomlinson, 1997; Turner et al., 1990). Families who experienced more stress and ambiguity were those who reported feeling less prepared for the admission (Tomlinson & Harbaugh, 2004; Tomlinson, Swiggum, & Harbaugh, 1999) or whose children were five years of age or younger (Tomlinson et al., 1999), were perceived to have lower levels of consciousness (Tomlinson & Harbaugh, 2004), or were perceived to be more severely ill (Tomlinson & Harbaugh, 2004; Tomlinson et al., 1999). History of previous PICU admission(s) did not decrease stress (Tomlinson & Harbaugh, 2004; Tomlinson et al., 1999).

Family systems theory was the framework for four previous studies of family stress in the PICU; according to this theory the boundary "defines the [family] system and represents the interface, or point of contact, between the system and other systems" (Whitchurch & Constantine, 2004). Investigators found that PICU families initially experienced boundary ambiguity (Mu & Tomlinson, 1997; Tomlinson et al., 1999), i.e., they were "uncertain…about who is in or out of the family and who is performing what roles and tasks within the family system"; the degree of ambiguity determines the level of family stress (Boss & Greenberg, 1984). *Boundary expansion* was necessary when the family felt threatened by the situation of their child's critical illness (Mu & Tomlinson, 1997; Tomlinson et al., 1999), and empowered health care providers, relatives, and friends to take part in family roles, tasks, and functions, assisting the family to maintain its integrity and meet the goals of the family system (Mu & Tomlinson, 1997). Nurses played an integral role in strengthening family boundaries by supporting parents' roles with their hospitalized child and other children, and their partnership with each other; acknowledging and supporting families to fulfill roles and responsibilities outside of the hospital; and promoting social support from other sources (Board & Ryan-Wenger, 2002; Mu &

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Tomlinson, 1997; Saied, 2006; Tomlinson & Harbaugh, 2004; Tomlinson et al., 1999; Tomlinson et al., 2012).

These studies were conducted early in the child's stay, usually within one to three days of admission (Board & Ryan-Wenger, 2002; Saied, 2006; Tomlinson & Harbaugh, 2004; Tomlinson et al., 2012; Tomlinson et al.,1999); the exception is a study in which families were interviewed as late as fifteen days after admission (in some cases after discharge from the ICU) (Mu & Tomlinson, 1997). Therefore little is known about how families may experience stress as their child's ICU stay becomes prolonged. Additionally, no family stress research has been reported in recent years describing the phenomenon in contemporary PICUs. The study described in this paper explored the experience of families whose children were hospitalized for a week or longer in the PICU. Findings will be discussed in light of previous research.

Conceptual Framework

An ecological model, entitled *Family Stress in Pediatric Critical Care: Living in Two Worlds* (see Fig. 1), was developed for this study; this type of model provides a framework for examining "multilevel functions and systems in relation to each other over time" (Bubolz & Sontag, 2004, p. 425). Based in previous PICU research and the investigator's experience in this setting, this conceptual model reflects the contemporary PICU environment and factors likely to be important to the population of children with long ICU stays, depicting the different environments within which families interact. It is particularly relevant for families with longer LOS since, as a child's critical illness becomes prolonged and one or more family members return home to resume routine functions, the family must learn to function within these two "worlds."

Purpose

The purpose of this mixed methods study was to describe sources of stress in families of children who had been hospitalized in the PICU for more than one week, extending knowledge about family stress in PICU beyond the first few days of their ICU stay.

Design

A variant of a convergent parallel design was used. In this type of design, qualitative and quantitative data are collected concurrently, analyzed separately, and then merged to create a more complete understanding of the phenomenon (Creswell & Plano Clark, 2011). Although both methods are typically prioritized equally, the present study was predominantly qualitative. Qualitative interviews explored sources of stress. Quantitative data were used to compare the number and type of stressful life events that families had experienced in the past 12 months (Family Inventory of Life Events, FILE) (McCubbin, Thompson, & McCubbin, 1996) and families' perceptions of the influence their child's critical illness had on family life and functioning (Family Systems Stressor-Strength inventory, FS^{3}I) (Berkey & Hanson, 1991).

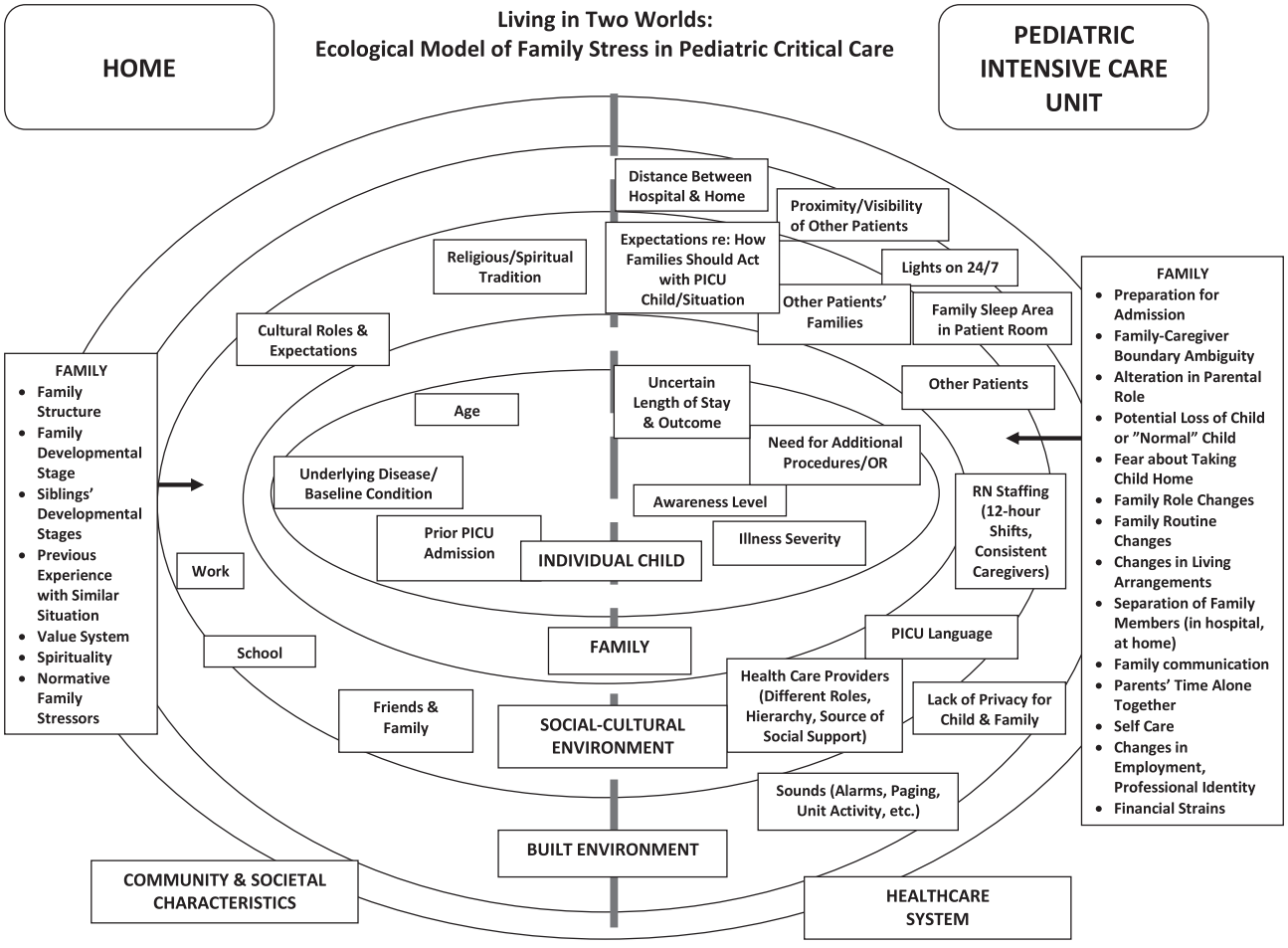

Fig. 1. Ecological model of family stress in pediatric critical care.
Adapted from: Bubolz and Sontag (2004).

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