

FAMILY STRESS IN LONG-TERM PEDIATRIC CRITICAL CARE:
A MIXED METHODS STUDY

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Dedication

This dissertation is dedicated to the families who so willingly shared their experiences with me. They have given me a window into their lives that has changed the way I look at the work we do every day in our children's hospital. I hope to honor their time and their trust by sharing these insights to help inform nurses' and other health care providers' understanding of the stress that families experience when their children are in the intensive care unit.

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Abstract

Hospitalization in the pediatric intensive care unit (PICU) is stressful for families and disruptive for their normal lives. As new technology has become available, the number of children requiring prolonged stays in the PICU has increased. This mixed methods study explored stress in families whose children were hospitalized in the PICU for more than one week, collecting data one to two weeks after admission, then four to five weeks later. The purpose was to describe sources of stress for families whose children require extended hospitalization in the PICU and explore how sources of stress change over time. Data collection included semi-structured interviews and completion of the Family Inventory of Life Events (McCubbin, Thompson & McCubbin, 1996) and Family System Stressor Strength Inventory (Berkey & Hanson, 1991) at each time point.

Nine parents of eight children participated in the first phase of data collection; two mothers participated in the second phase. Data analysis revealed the following themes related to Aim 1 (sources of stress): separation, not knowing, child's illness and distress, care and caring, emotional stress, physical stress, job and financial stress, and what we've been through before. Themes related to Aim 2 (change over time) were: stress builds, and stress decreases as the unknowns become known. Analysis of Time 2 data revealed similarities in sources of stress compared to Time 1, but there was a shift in the relative priority and contribution that each stressor made to the overall perception of stress as hospitalization became prolonged and the child's condition improved; participants reported aspects of care and caring as most important at this point. A new

subtheme in the original care and caring theme was also identified: considering the child's entire picture.

Findings demonstrated sources of stress directly related to the child's acute illness as well as stress resulting from the child's hospitalization and ongoing healthcare needs, all of which contributed to the perception of family stress. Over time, stress was compounded and there was a shift from the primary stressors of unknowns and separation of the family to stressors related to the care and caring provided by the team.

Table of Contents

Acknowledgements	i
Dedication	ii
Abstract	iii
Table of Contents	v
List of Tables	viii
Chapter 1: Introduction	1
Background	1
Need for the Study	3
Significance for Nursing	3
Study Aims	4
Conceptual Framework	4
Chapter 2: Literature Review	6
Introduction	6
Definitions of Family and Family Stress	7
Definition of Family	7
Definition of Family Stress	7
Theoretical Frameworks	8
Instruments	8
Family Stress Levels in PICU	9
Factors Influencing Family Stress	11
Child/Parent Characteristics	11
Uncertainty	11
Family Stress and Coping	11
Coping with the Ill Child	12
Coping with Siblings	13
Coping with Each Other	13
Resources and Social Support	13
Family Functioning	16
Timing of Data Collection	19
Change Over Time	20
Nursing Intervention	21
Summary	22
Chapter 3: Methodology	23
Convergent Parallel Design	23
Study Population	24
Setting	24
Sample	25
Timing of Data Collection	26
Recruitment	26

Data Collection	27
Subject Characteristics	27
Family Stress Measures	28
Data Analysis	33
Qualitative Data Analysis	33
Quantitative Data Analysis	34
Merged/Mixed Methods Data Analysis	34
Limitations	36
Ethical Considerations	38
Rigor	39
Chapter 4: Results	41
Introduction	41
Sample Characteristics	41
Aim 1: Sources of Stress	43
Theme 1: Separation	43
Theme 2: Not Knowing	55
Theme 3: Child's Illness and Distress	57
Theme 4: Care and Caring	61
Theme 5: Emotional Stress	71
Theme 6: Physical Stress	75
Theme 7: Job and Financial Stress	78
Theme 8: What We've Been Through Before	80
Aim 2: Change in Sources of Stress Over Time	89
Comparison of Stress Sources	89
Themes	92
Summary of Findings	101
Chapter 5: Discussion of Findings	102
Introduction	102
Discussion of Key Findings	102
Aim 1: Sources of Stress	102
Aim 2: Change in Sources of Stress	119
Population and Methodological Differences	124
Summary of Contribution of this Study	125
Critique of the Study	126
Strengths	126
Limitations	128
Implications for Practice	129
Implications for Future Research	132
Implications for Theory	134
Conclusion	134
References	136

Appendix A: Family Stress and Nurse Support in Pediatric Critical Care: A Pilot Study – Summary	144
Appendix B: Conceptual Model	145
Appendix C: Literature on Family Stress in PICU	146
Table C1: Family Stress Studies in PICU	147
Table C2: Theoretical Frameworks, Units of Interest, Units of Analysis	149
Appendix D: Consent Form	151
Appendix E: Family Background Data Collection Form	153
Appendix F: Interview Guide – Time 1	154
Appendix G: Interview Guide – Time 2	155
Appendix H: Approval Letters and Instrument Permission	156
Approval Letter – University of Minnesota IRB	157
Approval Letter – University of Minnesota Medical Center Nursing Research Council	159
Permission Letter – Family Inventory of Life Events	160
Permission Letter – Family Systems Stressor-Strength Inventory	161
Appendix I: Child and Family Demographics (Table I1)	162
Appendix J: FILE Data	165
Table J1: FILE Scores and Subscores Prior to this Illness/Hospitalization	166
Table J2: Change in FILE Scores in Relation to This Episode of Care	167
Appendix K: Comparison of Themes from Time 1 and Time 2	168

List of Tables

Table 1. Inclusion and Exclusion Criteria	25
Table 2. Themes and Subthemes	43
Table 3. Primary Source(s) of Stress Identified at Time 1	44
Table 4. Previous Hospitalizations and PICU Admissions	85
Table 5. Phase in Illness Crisis and Relationship to the Acute Illness/PICU Hospitalization	88
Table 6. Change in FILE Scores for Family 8	99

Chapter 1

Introduction

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; Turner, Tomlinson & Harbaugh, 1990). A number of studies have investigated the related stress for individual family members and patients including parental stress and post-traumatic stress disorder (Miles, Carter, Riddle, Hennessey & Eberly, 1989; Nelson & Gold, 2012; Shudy et al., 2006) as well as family stress (a complex phenomenon encompassing both individual and family level perceptions). The construct of 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 during the child’s pediatric intensive care unit (PICU) stay have been conducted early in the child’s stay, usually within three days of admission (Board & Ryan-Wenger, 2002; Saied, 2006; Tomlinson & Harbaugh, 2004; Tomlinson et al., 2012; Tomlinson, Swiggum & Harbaugh, 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). As new technology requiring

intensive monitoring and care over several weeks and months becomes available to sustain children's lives, the number of children requiring prolonged stays in the PICU has increased (Alkandari et al., 2011; Graf, Montagnino, Hueckel & McPherson, 2008; Staveski, Avery, Rosenthal, Roth & Wright, 2011; Typpo, Petersen, Hallman, Markovitz & Mariscalco, 2009). Recent data from the study site demonstrated that the percentage of children with PICU length of stay (LOS) greater than fourteen days increased from 5.7% in 2010 to 7.3% in 2014, with percentages as high as 8.3% in some years. In that five-year period, an average of 25 children each year had been treated in the PICU for more than 30 days (K. Pearson, personal communication, July 23, 2015).

The concept of pile-up of life events described by McCubbin, Thompson, and McCubbin (1996) asserts that stresses and strains on the family change as the crisis evolves – some related to the crisis, others related to normative transitions or prior family strains. A pilot study suggested that the stress experience for families whose children were hospitalized in the PICU for several weeks changed as the hospitalization was prolonged, as families balanced the demands of their child's illness and hospitalization with the need to maintain their other children and family responsibilities (Hagstrom, 2013). (See Appendix A for a brief summary of the pilot.)

If a family reaches a point at which it can no longer adjust to the accumulation of stressors and strains, the family and/or its members may experience negative consequences (McCubbin et al., 1996). This has been demonstrated with this population during a similar era of new technology in the 1970s and 1980s in which nurse researchers

demonstrated a negative impact over time for families with technology-dependent children (Patterson, Leonard & Titus, 1992).

Need for the Study

Technological advances and the resulting changes for critically ill children and their families necessitate research that explores family stress after the initial days of ICU hospitalization and facilitates understanding of the ways in which family stress changes when a child requires hospitalization in the PICU for weeks or months. Investigation of stressors directly related to the child's illness (e.g., uncertainty regarding course and outcome) as well as stress on the family that results from the child's hospitalization (e.g., change in family routines and functioning) are needed. Researchers must also give attention to child and family characteristics and history (e.g., child age, family structure, family developmental stage, previous experience in meeting crisis), as these factors are likely to influence the meaning that a family assigns to this experience (Ganong, 1995; Green, 1982; Hill, 1958).

Significance for Nursing

Nurses play an important role in supporting families of hospitalized children (Hopia, Tomlinson, Paavilainen & Astedt-Kurki, 2005; Maijala, Luukkaala & Astedt-Kurki, 2009; Peden-McAlpine, Tomlinson, Forneris, Genck & Meiers, 2005; Tomlinson et al., 1999; Tomlinson et al., 2012). Therefore, it is imperative that they understand the unique experience of long-term PICU families, given the integral role nurses play in recognizing and addressing stress. This is supported by the recommendation from an international consensus conference at which "evaluating the long-term psychosocial

impact of a child's critical illness on family outcomes" was ranked as the second highest research priority for pediatric critical care nursing practice (Tume et al., 2015, p. 179).

Study Aims

This mixed methods study explored 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. The specific aims of this study were to 1) describe sources of stress for families whose children require extended hospitalization in the PICU, and 2) explore how sources of stress change over time.

Conceptual Framework

A conceptual model, entitled *Family Stress in Pediatric Critical Care: Living in Two Worlds*, was developed as a framework for this study. (See Appendix B). This model reflects the contemporary PICU environment and factors that are likely to be important to the population of children with long ICU stays, as well as factors identified in previous research on family stress in the PICU setting. It is founded in human ecology theory which suggests that the family interacts with its environment, making up an ecosystem in which "the parts and wholes are interdependent" (Bubolz & Sontag, 2004, p. 425).

An important feature of the model is its depiction of the different environments within which families interact. As the child's critical illness becomes prolonged and one or more family members return home to resume some aspects of their routine functions, the family must learn to function within in these two "worlds" – the PICU and home environments. An ecological model is suited to this research because it provides a framework for examining "multilevel functions and systems in relation to each other over

time” (Bubolz & Sontag, 2004, p. 425). The present study and future research will contribute to further refinement of the model, with the intent that it will ultimately lead to explanation and prediction of how families relate to these environments.

Chapter 2

Literature Review

Introduction

Previous investigations of stress related to a child's PICU hospitalization have typically focused on the individual family member, with fewer investigating the family as a whole. While understanding the experience of individual family members is necessary and contributes to knowledge about the family's experience, we must also attend to the specific impact on the family unit. Therefore, the literature reviewed in this chapter will include only PICU studies in which the family was the unit of interest.

Studies meeting these criteria are summarized in Table C1. Of the seven papers, two examined results of a nursing intervention designed to decrease stress, while the remaining studies explored the stress experience of PICU families. Two investigators measured both individual and family level variables (Board & Ryan-Wenger, 2002; Saied, 2006); however, given the focus of this review, only outcomes and relationships related to family stress are reported.

In this chapter, theoretical considerations, including definitions of family and family stress, unit of interest, unit of measure, and instruments, are described as well as theoretical frameworks. Family stress levels and change over time are reported, as well as factors which influence stress. Relationships between family stress and coping, resources, social support, and family functioning are reviewed in addition to timing of data collection and change in family stress over time as reported in previous studies. Finally,

effects of an intervention to teach nurses how to incorporate practices to reduce family stress are described.

Definitions of Family and Family Stress

Definition of family. None of the reports indicated how the concept of family was defined within the research framework, and none stated the operational definition of family for the study. While all of these investigators reported the family as the unit of interest, there were differences in the definition of family implied by whom they chose as respondents and by the instrument items or interview questions selected for each study. Most data collection methods addressed the family as a whole, while two focused primarily on the parent-hospitalized child dyad (Tomlinson & Harbaugh, 2004; Tomlinson et al., 1999). This difference in focus was evidenced by interview questions such as “What has this experience been like for you and your family?” (Mu & Tomlinson, 1997) compared to those focused on parental role perception, parental autonomy, and enhancement of parental responsibilities (Tomlinson et al., 1999). Similarly, some quantitative instruments focused on the whole family (e.g., Family Inventory of Life Events, McCubbin et al., 1996) while others primarily considered the parental role with the hospitalized child (e.g., Family Nurse Boundary Ambiguity Scale-PICU, Tomlinson & Harbaugh, 2004). Table C2 provides a summary of each study’s theoretical framework, definitions related to family and family stress, and a comparison of the units of interest and measure.

Definition of family stress. Only one report provided a definition of family stress (Tomlinson et al., 2012). Saied (2006) combined a measure of family stress with a

measure of parent stress to construct her definition of stress. Tomlinson and Harbaugh (2004) and Tomlinson et al. (1999) defined health-related family boundary ambiguity, and described the tool they developed to measure this construct as one that offers a “new way of exploring family stress in PICU” (p. 407).

Theoretical Frameworks

Different theoretical frameworks and conceptual models formed the basis for each of these studies. They included grand theories (e.g., family systems, symbolic interactionism) and conceptual frameworks developed specifically for this setting (e.g., family-nurse boundary ambiguity).

Instruments

The instrument used to measure family stress in each quantitative study was consistent with its theoretical framework; they included the Family Inventory of Life Events (FILE) (McCubbin et al., 1996), a revised version of the FILE, and the Family Nurse Boundary Ambiguity Scale (FNBAS-PICU) (Tomlinson & Harbaugh, 2004). The FNBAS-PICU (previously called the Health-Related Family Boundary Ambiguity Scale) was developed specifically for this context while the FILE was developed and has been used in numerous populations and settings, including families in which a child has experienced illness (LoBiondo-Wood, Williams & McGhee, 2004; Tak & McCubbin, 2002).

The FILE, developed as an index of family stress, assesses the pile-up of life events experienced by a family, “the sum of normative and non-normative stressors and intrafamily strains” (McCubbin et al., 1996, p. 105). Normative data from previous

research permits interpretation of findings in light of previous investigations. The version of the FILE used by Saied (2006) was composed of two subscales (stressful family life events and intra-family strain); this shortened version provided limited opportunity for comparison of findings since it had been used in only one previous study.

Tomlinson and Harbaugh (2004) developed and tested the FNBAS-PICU to measure family stress in the PICU setting; this instrument was based on data generated in a grounded theory study of parental uncertainty in the PICU ($n = 13$) (Turner et al., 1990). Following establishment of content and face validity, psychometric testing was completed using responses from a sample of PICU families ($n = 157$). Factor analysis revealed four constructs consistent with the definition of family-nurse boundary ambiguity. These authors recommended this scale as a measure of “relational sources of stress and ambiguity for families of acutely ill children between the child’s family and the child’s health-care providers” which can supplement the Parental Stressor Scale: Pediatric Intensive Care Unit (PSS:PICU) and Parent Perception of Uncertainty in Illness Scale: Parent-Child Form (PPUS-PCF) “in studies in which the investigator wishes to explore a systemic view of the family experience in the PICU” (Tomlinson & Harbaugh, 2004, p. 408).

Family Stress Levels in PICU

While Mu and Tomlinson (1997) did not quantify family stress, they found that “all other experiences [associated with their child’s PICU hospitalization] exist directly or indirectly under the overarching shadow of a global experience of crisis” (p. 607). Other authors quantified the amount of stress that families experienced in this situation,

but limitations in measures and lack of comparative data limit the conclusions that can be drawn.

Mean FILE scores for PICU mothers in the Board & Ryan-Wenger (2002) study indicated that they were moderately stressed at the time of recruitment ($n = 31$) and six months later ($n = 17$); however, this was not unique to the PICU experience since mothers of general care unit and clinic patients were also moderately stressed at both time points. Since normative data are not available for the modified version of the FILE used by Saied (2006), the author compared scores from one study in which it was used for a community-based sample and found that scores in the comparative sample were higher (i.e., participants were more stressed) than in Saied's (2006) sample ($n = 74$). Since both versions of the FILE measure pile-up of life events, and data collection took place soon after PICU admission (before the consequences of this experience would typically manifest in ways measured by the FILE), it is likely that these findings reflected previous stress and not the stress on the family caused by the child's hospitalization.

Tomlinson et al. (1999) used the FNBAS-PICU to identify families with higher stress levels to participate in the qualitative portion of their study, using a median split to classify families as high or low scoring. For this scale which has a possible range of 14 to 70, the mean score for families with high scores was 39.62 while low-scoring families averaged 28.28. Scores for the entire sample were similar to those found during initial testing of the scale (Tomlinson & Harbaugh, 2004); however, the lack of published literature with other samples limits the conclusions that can be drawn about levels of stress in this study.

Factors Influencing Family Stress

Child/parent characteristics. Various patient and family factors were found to be associated with family stress. Tomlinson and Harbaugh (2004) and Tomlinson et al. (1999) ($n = 29$) found a positive relationship between family stress and parents' perception of child illness severity. Negative associations were demonstrated between family stress and the child's age (Tomlinson et al., 1999), family estimate of the child's awareness (Tomlinson & Harbaugh, 2004) and their perception of being well prepared for the admission (Tomlinson & Harbaugh, 2004; Tomlinson et al., 1999). However, no relationship was found between family stress and number of prior PICU admissions (Tomlinson & Harbaugh, 2004; Tomlinson et al., 1999).

Uncertainty. Tomlinson and Harbaugh (2004) demonstrated a relationship between family stress (FNBAS-PICU) and uncertainty (PPUS-PCF). This is consistent with Mu and Tomlinson's (1997) qualitative finding that parents' struggled with uncertainty about the child's condition, especially early in the hospitalization ($n = 10$).

Family Stress and Coping

Common themes in how families coped with the stress of PICU hospitalization were identified in this literature. Saied (2006) found that parents' coping was affected by the amount of stress they reported; those with more stress (PSS:PICU and stressful family life event subscale) demonstrated less use of coping behaviors. Three dimensions of parents' coping patterns emerged in Mu and Tomlinson's (1997) analysis: coping with the ill child, coping with siblings, and coping with each other. These dimensions were supported by findings from the other studies as well.

Coping with the ill child. Parents' coping included a desire to participate in comforting and connecting with their child. This helped meet the child's needs (since parents were best able to interpret the child's responses) and the parents' needs for comfort and a sense of family normalcy (Mu & Tomlinson, 1997; Tomlinson et al., 1999). They also expressed the need to know more complex information about lines, tubes, and alarms so they could make decisions about how to "safely establish and maintain the part of the protective family nurturing function left to them" (Tomlinson et al., 1999, p. 39). This is an example of how families reframed their roles to share caregiving with health care providers when they realized that the situation was beyond their knowledge, experience, ability, and control (Mu & Tomlinson, 1997).

The way in which nurses constructed caregiving influenced how stressful it was for parents to give up portions of their caregiving role. By fostering family normalcy, nurses were perceived as supplementing parents' roles while helping them retain their place in family functioning. However, families felt as if they were replaced by health care providers in situations in which their rights were not respected (Tomlinson et al., 1999); the perception of having their parental role superseded by health care providers led to feelings of helplessness (Mu & Tomlinson, 1997).

These findings correspond to literature on parent stress which has identified parental role alteration as the key contributor to parent stress (Board & Ryan-Wenger, 2000). Therefore, it is not surprising that both qualitative and quantitative data reviewed for this paper revealed a relationship between parent stress and family stress. Thematic constructs identified by Mu and Tomlinson (1997) and Tomlinson et al. (1999) as

comprising family stress contain concepts similar to those measured by the PSS:PICU which is commonly used for research with parents in this setting. Tomlinson and Harbaugh (2004) found a positive correlation between family stress (FNBAS-PICU) and the parental role alteration subscale of the PSS:PICU, and Board and Ryan-Wenger (2002) demonstrated a positive correlation between family stress scores (FILE) and parent stress (PSS:PICU) and symptom scores (Symptom Checklist-90 Revised).

Coping with siblings. Parents were equally concerned about maintaining their protective role with their other children, and dealt with this by relinquishing their caregiving role to other family members in order to normalize the siblings' experience. They empathized with the siblings' perception of the situation and experience, and sought to maintain relationship with them through frequent interaction (Mu & Tomlinson, 1997).

Coping with each other. Parents provided mutual support for each other through the experience of having a child in the PICU. They identified their partnership as the strongest of all the support they experienced, meeting their mutual needs and creating a supportive alliance as they interacted with the health system (Mu & Tomlinson, 1997).

Resources and Social Support

Saied (2006) used a shortened version of the Inventory of Socially Supportive Behaviors (ISSB) (Barrera, Sandler & Ramsay, 1981) to measure social support. Concepts measured by this instrument (e.g., "gave you information to help you understand a situation you were in") were reflected in themes that emerged from interviews in which families identified extrafamilial resources (Mu & Tomlinson, 1997) or nursing interventions to help reduce stress related to the interface between families and

nurses (Tomlinson et al., 1999). This suggests that families perceived nurses as a source of social support as conceptualized by the ISSB.

Parents in Mu and Tomlinson's (1997) study reported that information they received from health care providers about the child's condition affected their ability to synthesize the experience of having a child in the PICU. Not only the provision of information, but the quality of information and the way in which it was communicated influenced whether parents felt supported (Mu & Tomlinson, 1997; Tomlinson et al., 1999). Families expressed comfort sharing decision-making with medical and nursing staff if they felt respected, but felt excluded when health care providers did not respect their input or explain medical decisions. However, they perceived risks to demanding information and didn't know what their rights were (Tomlinson et al., 1999).

Although families identified health care providers as a source of support, they carefully scrutinized caregivers' attitudes and the quality of care provided. "Parents perceived the child under the best professional care only when they observed that primary caregivers were knowledgeable, attentive, responsible, empathic, and worked as a well-coordinated team" (Mu & Tomlinson, 1997, p. 620). Nurses helped reduce family stress when they fostered family normalcy by extending natural ways of comforting children and treating them as they would under normal (non-PICU) circumstances, thereby recognizing the child within. Parents were more likely to trust those nurses to supplement their parental roles (Tomlinson et al., 1999), which represented an important aspect of coping with the ill child.

Parents were empowered when they received support from resources outside their family that helped increase their energy level, relieve their concern, and sustain their hope. These resources were supportive for parents, other family members, and family functioning overall. Families also used religion to reframe the meaning of the situation (Mu & Tomlinson, 1997).

When Saied (2006) collected data from 74 parents 24-48 hours after cardiac surgery, she found that parents with more stress (PSS:PICU and stressful family life event subscale) demonstrated less use of social support. This appears to conflict with Mu and Tomlinson's (1997) qualitative findings which implied that most families identified sources of social support. A number of factors may contribute to this potential difference in interpretation. First, Mu and Tomlinson (1997) did not differentiate families by stress level, so it cannot be determined whether families with more stress were more or less likely to avail themselves of social support. Also, the timing of data collection was different in these two studies: 24-48 hours after cardiac surgery (Saied, 2006) versus 2-7 or 12-15 days after admission (Mu & Tomlinson, 1997). It is possible that families in Mu and Tomlinson's (1997) sample had more time to assess and take advantage of social support, consistent with Saied's (2006) interpretation that they may need to "settle into the experience before they can assess the support resources available" (p. 31).

In testing relationships between variables, Saied (2006) found that social support moderated the relationship between family stress (FILE subscales) and family functioning. However, it did not moderate the relationship between family stress and

communication, or between parent stress (PSS:PICU) and family functioning (Saied, 2006).

Family Functioning

Concepts from family systems theory formed the framework for a number of these PICU studies in which boundary ambiguity was foundational to the concept of family stress. According to systems theory, the boundary “defines the [family] system and represents the interface, or point of contact, between the system and other systems” (Whitchurch & Constantine, 2004, p. 333). Boundary ambiguity is “a state in which family members are uncertain...about who is in or out of the family and who is performing what roles and tasks within the family system” (p. 2); the degree of ambiguity determines the level of family stress (Boss & Greenberg, 1984). In the analysis of text from family interviews soliciting information about nursing interventions to reduce stress, Tomlinson et al. (1999) cited strengthening family boundaries as being “more than any other [theme], related to a holistic perspective of the family as a functioning system embracing the sick child, the family purpose, family goals, and family member social roles and maintaining integrity” (p. 41).

Interactions of the family with “the outside world,” (i.e., boundary transactions), helped the family system reach its goals of self-maintenance and integrity (Mu & Tomlinson, 1997). Factors affecting parents’ perceptions of their interactions with nurses included the motive of the caregiver (Mu & Tomlinson, 1997) and the degree of honesty they perceived. Complete honesty about the child’s condition, even at the risk of

offending family members, was essential for families to trust, feel included, and be able to leave the hospital to attend to other family responsibilities (Tomlinson et al., 1999).

Families also appreciated when nurses provided detailed planning for the day, which helped them decide how much time to spend at the bedside versus fulfill other family responsibilities or spend time with other children (Tomlinson et al., 1999).

Whenever families were able to focus on more than just the patient, “the family system was normalized and tension was released” (Mu & Tomlinson, 1997, p. 621), and they were able to “refresh and regroup from...[a] world overwhelmed with concern for a critically ill child” (Tomlinson et al., 1999, p. 42).

Supporting was another theme identified as strengthening family boundaries. This included reassurance about what to expect, nurses’ availability by phone, help with other needs (e.g., providing a meal voucher, as both a source of financial support and acknowledgement of parents’ integral role on the team), supervised day care for siblings so families could be together at the hospital, and access to resources for parents to work in or near the child’s hospital room and thus maintain work roles and support family goals (Tomlinson et al., 1999).

The concept of boundary expansion was central in both Mu and Tomlinson’s (1997) and Tomlinson et al.’s (1999) studies. Expansion of the boundary was necessary when the family felt threatened by the situation of their child’s critical illness. This empowered health care providers, relatives, and friends to take part in family roles, tasks, and functions, thus assisting the family to maintain its integrity and meet the goals of the family system (Mu & Tomlinson, 1997). The ways in which nurses cared for the child

and family affected parents' willingness to expand the family boundary and accept nurses into the family unit (Mu & Tomlinson, 1997; Tomlinson et al., 1999). The importance of the manner in which nurses related to families, and its relevance to their experience of stress, was apparent in several of the themes that emerged from these studies.

The strategies of comforting/connecting, needing to know, and respecting family rights, were essential for parents to maintain their relationship with the child because they helped reassure parents about their relationship with the child and their executive function in the family (Mu & Tomlinson, 1997; Tomlinson et al., 1999). This in turn decreased family boundary ambiguity and moved the family toward equilibrium (Mu & Tomlinson, 1997), which suggests that families' stress decreased as their functioning improved.

Synthesis of research on the relationship between family stress and functioning reveals some potential differences, possibly related to timing of data collection. Findings from qualitative research that confirmed the existence of a family stress perception (Mu & Tomlinson, 1997) and enumerated nursing interventions to decrease family stress by supporting family functioning (Tomlinson et al., 1999) suggested a negative association between family stress and family functioning. This is consistent with Saied's (2006) finding that families with more stress (FILE subscales) had less healthy family functioning and communication (Family Assessment Device); a high family stress score (specifically the stressful family life events subscale) was the strongest predictor of decreased family communication. In all of these studies, perceptions were documented soon after admission and results were different than Board and Ryan-Wenger's (2002)

findings six months after hospitalization, when mothers with lower family stress scores (FILE) perceived their family's functioning to be worse over time. (The authors suggested that this may be because the child's illness had a significant effect on their perception of family functioning, despite no increase in pile-up of life events.)

Timing of Data Collection

In the majority of investigations, data collection occurred within one to three days of PICU admission. Four descriptive studies collected data at a single point in time: one within 24 to 72 hours of PICU admission; another within 24 to 48 hours of cardiac surgery (although it's not reported whether the children had been in the PICU preoperatively); and another after the child had been in the PICU for at least 24 hours. The final non-intervention study divided the families into two groups: five families were interviewed two to seven days after admission and the remaining families were interviewed 12 to fifteen days after admission. The authors stated that this "allowed the data to hold both an experiencing and an experienced perspective" (Mu & Tomlinson, 1997, p. 614), implying that the children had been discharged from the PICU at the time of the interview, although this was not specifically stated. Board and Ryan-Wenger (2002) collected data at four points in time, one within 24 hours of PICU admission and the remainder after discharge; the final time point was six months after discharge.

The nursing intervention described by Peden-McAlpine et al. (2005) and Tomlinson et al. (2012) was performed 12 to 36 hours after admission. Families and nurses participated in data collection at various times: immediately after the intervention, three days later, and three weeks after the intervention.

Change Over Time

The concept of change in family stress over time is supported by Mu and Tomlinson's (1997) conclusion that families of critically ill children are engaged in an *active process* of dealing with the stress associated with their child's hospitalization. Only one published study (Board & Ryan-Wenger, 2002) measured change over time, finding an increase in FILE scores six months after discharge compared to time of PICU admission. Since these authors also studied two comparison groups (i.e., general care unit and clinic patients), they were able to demonstrate that this was not unique to PICU families, since all three groups experienced a similar increase.

Although change in stress over time for families of children who remain hospitalized in the PICU for prolonged periods has not been published, a pilot study conducted with two mothers and two nurses who were their children's consistent caregivers suggests that there were differences in sources of stress when they recalled their experience in the early days following admission compared to the time of the interviews (three or seven weeks after admission). Their focus in the first several days was on the crisis of the child in the hospital (e.g., high acuity, uncertainty regarding moment-to-moment changes). As the initial crisis resolved and the father and siblings returned home, stress on the family system became more apparent (Hagstrom, 2013). This may reflect a broadening of focus from the parent-child dyad to the entire family system over time.

Nursing Intervention

Findings from exploratory studies were used to develop an intervention to decrease family stress in PICU, which was described in two publications. One was dedicated to a comprehensive description of the intervention's design and included limited detail regarding results of the pilot (Tomlinson et al., 2012) while the second provided a full description of qualitative findings from interviews with nurse participants ($n = 8$). (Peden-McAlpine et al., 2005). These investigators used a reflective practice intervention (RPI) to teach nurses how to incorporate a family nursing intervention into their practice, using principles identified in Tomlinson et al.'s (1999) study. The intervention led to nurses acknowledging and reframing preconceived ideas about families, which resulted in understanding the need to appreciate each family's unique situation and a change in attitudes about families and their role in caregiving.

Another effect of the RPI was that nurses recognized the meaning of family stress. This involved acknowledging how continuity of care helped them develop relationships with family members and connect with the family as a whole. Families with whom they interacted after the RPI expressed more trust and decreased stress and were therefore able to leave the hospital to take care of other family needs. Nurses also reported a heightened awareness of the uniqueness of each family's stress and focus on measures to reduce stress based on the family's situation.

Finally, nurses reported increased interaction and information-sharing with families, which fostered development of trusting relationships in a shorter period of time. Nurses also became more open to including the family and relinquishing control of the

child's care. Families responded positively to this behavior, further reinforcing the nurses' recognition of the importance of incorporating the family into nursing care (Peden-McAlpine et al., 2005). Tomlinson et al. (2012) reported a slight decrease in family stress immediately after the intervention, but no statistically significant difference between groups; families experienced gratitude for nurse empathy, increased comfort in nursing presence, and increased hope.

Summary

Mu and Tomlinson (1997) concluded that their most important finding was “strong evidence of a collective perception of family stress within the family... a phenomenon that is both holistic and multidimensional and represents a family process variable” (p. 617). This concept is supported by the findings of this review of literature on family stress in PICU. The scientific merit of these studies and their complementary nature provide an excellent foundation for future research extending the understanding of family stress in pediatric critical care.

Chapter 3

Methodology

This chapter provides a description of the study's mixed methods design and analysis as well as details of recruitment and data collection rationale and procedures. Limitations, ethical considerations, protection of human subjects, and strategies used to enhance rigor are also discussed.

Convergent Parallel Design

A variant of a convergent parallel design was used for this study. 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). Both methods are typically prioritized equally. However, the present study was predominantly qualitative (QUAL + quan); the capital letters used in this notation indicate relative priority of the methods, (i.e., quantitative methods are secondary) and the + indicates that the methods occur at the same time (Creswell & Plano Clark, 2011).

Qualitative interviews explored sources of stress and how they changed over time. Quantitative data were used to compare the number and type of stressful life events that families had experienced in the past 12 months (FILE) and families' perceptions of the influence their child's critical illness had on family life and functioning (FS³I), measured at two points in time (within five days to two weeks of ICU admission and four to eight weeks later). Although the small sample size prohibits use of the quantitative data as a source of statistical inference, data from the instruments were used for

description. Instruments were also used to elicit information (both qualitative and quantitative) about stressors that may not have emerged otherwise and to trigger additional insights during the interviews (Sandelowski, 2000).

The focus of this research is the family system, which is made up of individual members but must be understood as a whole instead of its component parts (Whitchurch & Constantine, 2004). For purposes of this study, the family is operationally defined as the parent(s) and child(ren) living in the household; key informants are the biological, adoptive, or step parents who live with the child. Family demographic information was collected to describe each family's structure and who they consider to be family. Parents were asked to represent their perceptions of the impact of the child's ICU hospitalization on the family system, not only on themselves as individuals or other family members, since what affects one member of the system affects the family as a whole (Whitchurch & Constantine, 2004).

Study Population

Setting. Participants were recruited from a 12-bed PICU and a 12-bed pediatric cardiovascular intensive care unit (CVICU) at the University of Minnesota Masonic Children's Hospital. Both units admit children with a variety of diagnoses, ages, and LOS. Each unit has a subset of patients who require ICU hospitalization for extended periods of time, although the reasons for hospitalization vary considerably (e.g., multi-system organ failure following bone marrow transplant, cardiac failure requiring ventricular assist device while awaiting heart transplantation, critical airway requiring availability of a specialized team).

Sample. A convenience sample of families from the PICU and CVICU were recruited for this study. The principal investigator (PI) spoke with the charge nurses each weekday to identify potential participants. Families of all ICU patients with current LOS of five days to two weeks, who were anticipated to require hospitalization for an additional four to eight weeks, were screened for eligibility with the patient's nurse.

Inclusion and exclusion criteria are presented in Table 1.

Table 1

Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
ICU LOS 5 days to 2 weeks at time of recruitment	LOS > 2 weeks on another hospital unit during this admission
Anticipated hospitalization 4-8 weeks after study recruitment	Acute event within past 48 hours (e.g., resuscitation, surgery)
One or both parents present	Suspected child abuse or neglect
Biological, adoptive, or step parent(s)	Do-not-resuscitate order
Able to read and speak English fluently	End of life situation
	Foster parents
	Parent < 18 years of age

Note. ICU: intensive care unit; LOS: length of stay.

The inclusion criteria were designed to help control for other potential contributors to stress and to capture each family's experience at a similar time in the child's course. Children who were transferred from another unit where they had been hospitalized for two or more weeks prior to ICU admission were excluded, since it was anticipated that their families would have already experienced changes related to the hospitalization. Parents of children who had a recent event (e.g., resuscitation, surgery) were not asked to participate in the study within 48 hours of such events, to allow them to focus on the immediate needs of their child and family. Families of children with

suspected child abuse or neglect, at the end of life, or with do-not-resuscitate orders were excluded since the stressors associated with these situations are likely different than those of other ICU families.

Foster parents were not included due to the significant variability among foster care situations in length of time that the family has provided care for the child and degree of integration of the child into the family. Parents less than eighteen years of age were excluded since sources of family stress are likely different for teen parents given their normative developmental stage.

Timing of data collection. Since previous research indicates that family stress changes over time following an event, it was important that initial measures and interviews with each family be conducted at a similar interval following ICU admission. Waiting to collect data until five days to two weeks after admission was intended to avoid burdening parents who were dealing with the initial crisis of ICU hospitalization, while ensuring that they could easily recall their experiences since admission.

By the second data collection period (four to eight weeks later), it was anticipated that families would have adjusted to the initial effects of the child's illness and to their roles in the hospital, they would have resumed some of their routines (possibly in a modified form), and stress on the family system may be more apparent.

Recruitment. For families who met eligibility requirements, the patient's nurse provided the family with information regarding the research and offered the opportunity to participate, referring interested families to the PI to obtain consent. Both parents were invited to participate, and one could participate even if the other declined. Only one

couple chose to both participate in the research, electing to be interviewed together.

Following written consent (see Appendix D), parents who met inclusion criteria provided demographic information about the child and family, then completed data collection.

Data Collection

Data collection was designed to include complementary qualitative and quantitative approaches conducted with each family at two points in time – upon enrollment in the study and four to eight weeks later.

Subject characteristics. Characteristics of the hospitalized child collected from the medical record included age, gender, primary medical diagnosis, co-morbidities, ICU LOS, hospital LOS, reason that ICU care was required (i.e., multiple system organ failure, critical airway, ventricular assist device, other reasons), current level of sedation/awareness, technologies currently required (as an indicator of illness severity), number of operating room or cardiac catheterization procedures, number of resuscitation events, and number of intubations. Information about previous hospitalizations was collected from participants, including the number and reasons for previous hospitalizations (ICU and general care unit).

Participants completed the family background data collection form at the beginning of the initial data collection session, prior to the interview. Family characteristics included marital status, family composition (parents, siblings, others they identify as family), ages of family members, employment/profession, and whether the admission was planned. They were also asked where each family member was staying,

place of permanent residence and its distance from the hospital, and, if applicable, how long they had been staying in the metropolitan area. (See Appendix E.)

Family stress measures. Sources of family stress were measured in three ways – parents participated in semi-structured interviews (qualitative), in addition to completing the FILE (quantitative) and FS³I (quantitative and qualitative). Data collection methods were designed to elicit perceptions of sources of stress on the family unit, instead of the overall experience of long-term hospitalization. This assured that qualitative and quantitative data collection strategies addressed the same concepts so that results from both sets of data could be merged in a meaningful way, an important consideration in mixed methods research (Creswell & Plano Clark, 2011).

The interviews started with the request: “Tell me about the things that make this experience (having your child in the ICU) stressful for your family.” Nonverbal prompts and probes were used to encourage in-depth responses, allowing participants to talk freely about their experiences and perceptions. This discussion was followed by administration of the FILE. Participants were instructed to choose “yes” or “no” to indicate if each change happened to anyone in their family in the past 12 months; for items for which they indicated “yes,” it was requested that they also note if that change had occurred in the time since the child’s hospitalization for critical illness. Because the researcher was present during instrument completion, most participants spontaneously shared additional insights or explanations about why they indicated “yes” on specific items; some asked questions about how to interpret the question, which provided additional opportunity to understand their perspective on family life events. Following

completion of the FILE, the researcher briefly reviewed the FILE and asked participants about their perceptions of the overall number of life events and those that had changed since the child's admission. For some families, this led to further discussion about additional pileup not reflected in the FILE (e.g., "member changed to new job/career" was true for more than one family member) and/or the relationship between the number of baseline life events to the present experience of having their child in the ICU.

The FS³I was administered after completion and discussion about the FILE. Participants were asked to circle the number (between one and five) that best described the influence their child's hospitalization in the PICU had on their family's life and how they perceived their family's overall functioning. Participants were encouraged to write or discuss their comments about each question; although some wrote comments, the majority chose to verbalize their thoughts and rationale for their numeric responses while they completed the instrument. These comments were recorded and transcribed as part of the interviews. (The couple that participated together did not verbalize their comments while completing the instruments, but did briefly compare responses on the FILE after completion.)

After completion of both instruments and related discussion, a topic guide was used to elicit responses to additional questions about potential sources of stress or alleviators of stress identified in the study framework. This included parent role, time spent together as a couple, self care, working with hospital staff, the child's future, the ICU environment, and spiritual beliefs and values. In many cases, the participants had already volunteered information about these topics in the course of answering the first

interview question and completing the instruments. Finally, participants were asked, “What other things do you think are important for me to know about your family’s experience?” (See Appendix F for order of discussion/data collection.)

A second phase of data collection was planned with each participant four to eight weeks after their initial participation, using the same data collection strategies as those used in the first phase. Questions for the semi-structured interviews in this phase focused on whether parents perceived a change in sources of family stress since the initial data collection, beginning with the request to “Tell me about how sources of stress are the same or different for your family since the last time we talked.” The same interview methods described above were used to elicit information about the family’s change in sources of stress. They were then reminded of the primary themes that they had shared in the first phase of data collection and asked if they were the same or different; additional sources of stress were also elicited. (See Appendix G.)

Interviews and discussions regarding instrument responses were audio recorded and transcribed verbatim by a transcriptionist with extensive experience working with interview recordings. Transcripts were reviewed with the audio recordings to verify authenticity. Following each interview, the PI recorded field notes describing observations made during the interviews (e.g., participant behaviors) and documenting the researcher’s experiences and reflections (e.g., difficulty hearing about negative family-staff interactions). Some observations led to minor changes in data collection techniques with subsequent participants (e.g., actively promoting discussion during instrument completion to elicit greater depth). Field notes reflected an ongoing analysis

of potential themes, as well as similarities and differences in responses and factors which may explain those similarities and differences (e.g., family stage as an important factor in which sources of stress emerged); these themes and related factors informed the formal analysis of the data.

Interviews. The decision to allow parents to choose whether to be interviewed separately or together was made to maximize the potential advantages of individual and dyadic interviews. While individual interviews may promote maximum expression of individual views and provide information on how each parent experiences this event differently, dyadic interviews may offer the additional insight of how parents mutually construct and negotiate meaning around this experience (Reczek, 2014). Given the exploratory nature of this research, information from each type of interview offers unique insights into the phenomenon in addition to informing decisions about how to conduct future studies in this setting.

Instruments. The FILE consists of 71 yes/no items, grouped into nine subscales: intrafamily strains (including the dimensions of conflict and parenting strains), marital strains, pregnancy and childbearing strains, finance and business strains, work-family transitions and strains, illness and family “care” strains (including illness onset and child care, chronic illness strains, and dependence strains), losses, transitions “in and out,” and legal. The overall scale reliability (Cronbach’s alpha) is .81 with the subscale scores varying from .73 to .30. Validity was established by performing discriminant analyses comparing low-conflict and high-conflict families who had a child with myelomeningocele or cerebral palsy; high-conflict families in each of these groups were

found to have significantly higher pile-up of life changes compared to low-conflict families (McCubbin et al., 1996).

The FS³I is a 53-item Likert-type questionnaire designed to identify family members' perceptions of stressors and strengths within their family. It includes three parts: family systems stressors (general), family systems stressors (specific to a stress-producing situation), and family systems strengths (Berkey & Hanson, 1991). The authors gave permission to use only the 12-item family systems stressors (specific) section for this study. Interrater agreement on conceptual fit and clarity of items was used to assess content validity for this instrument; conceptual fit was 80% and 63% of items met predetermined criteria for clarity. Reliability has not been reported (Touliatos, Perlmutter & Holden, 2001). This instrument has not been used in previously published PICU studies. However, it may be better suited to answer the questions posed in this research than instruments previously used in this context as it may provide a more effective method for eliciting responses specific to the family system and may be more sensitive to change over time.

Both mothers and nurses who completed these instruments during a pilot study identified that they considered them relevant to the topic of this research. Use of the instruments also served to stimulate additional discussion about the impact of the hospitalization and child's illness on the family system, eliciting insights that did not emerge during the semi-structured interviews conducted prior to completion of the instruments (Hagstrom, 2013).

Data Analysis

One of the features of the convergent parallel design is the analysis of quantitative and qualitative data independently (Creswell & Plano Clark, 2011). In order to facilitate independent analysis in this study (in which families enrolled and completed participation at different times over a period of several months) and to take advantage of the iterative nature of qualitative research methods, interviews were transcribed and reviewed throughout the data collection period. Interview questions were added or revised based on this review. Complete analysis of qualitative data was conducted after the study was closed and all eligible participants had completed both phases of data collection. Quantitative analysis was conducted separately. Finally, qualitative and quantitative results were merged and interpreted in an effort to provide a more complete understanding of the participants' stress experience over time.

Qualitative data analysis. The approach for analysis described by van Manen (1997) for uncovering or isolating thematic aspects of a phenomenon was used—including seeking the fundamental meaning of the text as a whole, then identifying statements or phrases that “seem particularly revealing about the phenomenon or experience being described,” and reviewing each sentence or sentence cluster to determine what each reveals about the phenomenon (p. 92). From these analyses, common themes related to sources of stress in PICU families could be discerned.

Interview transcripts from Time 1 were analyzed in isolation before analyzing across all Time 1 transcripts. Texts from each interview were compared and contrasted. Patterns linking the themes were identified as described by Diekelman and Allen (1990),

endeavoring to balance the parts against the whole throughout the process. Examination of key patterns included comparison of responses based on family developmental stage, family structure, previous experience with hospitalization and/or a child's special health care needs, and distance from home to the hospital. Following analysis of Time 1 interview transcripts, the same process was used to analyze each Time 2 transcript in isolation then compared and contrasted. Finally, themes from Time 1 were compared and contrasted to those from Time 2.

Quantitative data analysis. Child and family characteristics were used to describe the sample. FILE and FS³I responses were examined to identify similarities and differences in responses to individual items across families and between the couple that participated together, each completing the instruments independently. FILE scores were compared to normative data, categorizing each family's score as low, moderate, or high for developmental stage according to cutoff scores established using data from 1140 couples representative of seven stages of the family life cycle for which moderate stress levels were one standard deviation above and below the mean; low stress levels were more than one standard deviation below the mean; and high stress levels were more than one standard deviation above the mean (McCubbin et al., 1996). Change over time was examined within each family, and the types and sources of stress (individual items and subscales) were compared.

Merged/Mixed methods data analysis. Qualitative and quantitative data were compared within and across families to assess how they relate. The small sample size and the design of the study (i.e., discussing responses and insights during completion of the

instruments) permitted matching quantitative data (FILE and FS³I numeric ratings) to qualitative data for each family, which allowed for a more “fine-tuned” synthesis or comparison and a potentially more valid analysis than if findings were compared only on a group basis (Bazeley, 2009, p. 94).

Specifically, findings from the qualitative and quantitative strands were compared for each family (i.e., responses to individual items on the FILE and FS³I and themes from qualitative analysis). Key areas of the FILE that were compared to interview themes were in the “intrafamily strains” and “illness and family ‘care’ strains” subscales. Items on the FS³I were also examined for potential relationships to qualitative findings, including: extent to which family is bothered by this stressful situation; effect on family’s usual pattern of living; effect on ability to work together as a family unit; success dealing with similar concern in the past; effect on family’s future; and physical and mental health status of each member and the family as a whole. Each family’s responses to the FS³I questions (e.g., regarding success dealing with a similar concern in the past) were also compared to their total FILE score and subscores, looking for potential associations.

In addition, cases (i.e., individual families) were sorted according to scores on the FILE looking for patterns in the qualitative findings within each subgroup and then compared across subgroups (e.g., those with low scores compared to those with moderate scores, as defined by normative data for each stage in the family cycle). Numeric ratings for individual items on the FS³I were examined within and across families, seeking patterns in responses and potential relationships to qualitative findings (e.g., comparing parents who rated how much their family was bothered by this situation as high compared

to those who rated it low). This use of standardized scale information can help provide context for participants' statements, even in a small sample (Bazeley, 2009), and the resulting comparative analysis enhances integration of findings, as it may reveal that some groups talk about a particular topic more often than others; different groups may talk about different topics or raise different issues; or different groups may talk about the same topic in very different ways (Bazeley, 2010). Finally, cases were sorted according to degree of change over time in number of life events (FILE scores) and analyzed in light of qualitative findings to further enhance integration of findings.

Limitations

Although recruitment included both mothers and fathers, except for one couple, only one parent from each family participated in the research due to other responsibilities and limited availability. Participants were asked to speak for the family, but since the “family has dynamic and emergent properties that cannot be sufficiently studied by asking one respondent to describe the family experience” (Uphold & Strickland, 1989, p. 408), collection of data from an individual member limits the perspective offered on how this experience affected the family. However, Mu and Tomlinson (1997) found that family members experiencing a PICU admission “share with each other what they think is happening in the family, what is happening to each member, the relationships between members, and their interaction with the environment” (p. 624).

Similar to previous PICU family research, the majority of participants were mothers since they were more frequently present at the hospital. Because of the gendered nature of family roles, the mother's perspective may not be representative of the family.

All of the participants were married, biological parents of the hospitalized child; therefore the impact of critical illness on families with other family structures (e.g., single parents, step parents) is not represented in these findings. Exclusion of parents who did not speak or read English limited the cultural and ethnic diversity of the sample. The small sample size and potential for selection bias prohibits generalization to a broader population, particularly given the inherent diversity in families in terms of structure, ethnicity, and culture.

The instruments used for this study were not designed for the PICU; although the FILE has been used for previous research in this setting, it has not been tested in a sample of long-term PICU families. Reliability has not been reported for the FS³I, and there is no published literature on its use in the PICU setting. Therefore, it is possible that these instruments do not accurately measure the concepts of interest in a way that is relevant for this population and/or did not prove sensitive to change over time. However, merging analysis of qualitative with quantitative data facilitated understanding of instrument results which helped to mitigate this risk.

Since the same instruments and similar interview questions were used at each time point, participants were sensitized to the instruments and interview questions; this may have influenced responses during the second phase of data collection. Attrition was also a significant factor as the majority of children had been discharged prior to participation in the second phase of the study. Time 1 data from these families were included in the analysis but Time 2 data were not available for comparison over time.

Ethical Considerations

Families who participated may have found benefit in talking to the PI about their stress; it may have decreased anxiety and promoted coping. However, it may also have increased uncomfortable feelings. The timing of data collection, allowing them to become accustomed to the situation, and excluding families whose children had had a recent acute event, helped mitigate this risk. Resources were offered to families who were interested in speaking to a social worker or other professional to address psychosocial needs that were raised during study participation. One mother was referred to the nurse manager to address concerns about team communication and nursing assignments. Another risk specific to family research is that one family member may reveal what another considers private. Since the parents who both chose to participate were interviewed together, they were both aware of what the other had shared.

Approval for the study was obtained from the Institutional Review Board and the Nursing Proposal Review Committee of the study site. (See Appendix H.) Participants were provided with information regarding the study and written informed consent was obtained prior to participation. They were reminded that they may refuse to answer any questions or discontinue participation in the study at any time without any effect on their relationship with the researcher, caregivers, or the hospital. Interviews were conducted in a consultation room on the unit, to provide privacy while maintaining proximity to the child so the parent could respond if an issue required their attention during data collection. One exception is the interview conducted privately in the patient's room

during the second phase of data collection with a mother who needed to stay with her child to comfort her.

All consents, documents with patient or family identifiers, field notes, audio recordings, and transcripts were kept in a locked file in the PI's office; electronic files were encrypted. Identifying information was removed from transcripts during transcription. Audio recordings will be destroyed and unidentified data will be kept in electronic and paper format until analysis is complete. When publishing the findings, attention will be given to ensuring that participants cannot be identified either by name or by providing sufficient detail such that a particular person could be identified.

Rigor

Lincoln and Guba's (1985) criteria for trustworthiness of a qualitative study provide the framework for the design and reporting of this research: credibility, dependability, confirmability, transferability, and authenticity. Credibility involves conducting and reporting the research in a way that offers confidence that "participants' experiences and context are represented in a believable way" (Polit & Beck, 2012, p. 586). Strategies to ensure credibility included sampling until data saturation was achieved and reflexive journaling to support presentation of detailed descriptions of the data collection and analysis. Documentation of the decision trail was used to ensure dependability (i.e., "stability of data over time and conditions," Polit & Beck, 2012, p. 585). Additionally, method triangulation, "use of multiple methods to collect and interpret data about a phenomenon, so as to converge on an accurate representation of reality," served to enhance dependability (Polit & Beck, 2012, p. 745).

In addition to these strategies, verbatim transcription of interview audio recordings helps ensure that the findings “reflect the participants’ voice and the conditions of the inquiry, not the researcher’s biases, motivations, or perspectives” (Polit & Beck, 2012, p. 585), thus enhancing confirmability. Transferability of findings to other settings or groups is supported by reporting the methodology, participants, and research setting, along with quotes which support insight into the sources of stress that families experience in this setting. All of these strategies provided the content necessary to develop a report that has authenticity, conveying “the feeling tone of participants’ lives as they are lived” (Polit & Beck, 2012, p. 585).

Chapter 4

Results

Introduction

The purpose of this chapter is to describe characteristics of the study sample and present the results of content analysis of the interviews in addition to instrument results. Demographic characteristics of the hospitalized child and their families are presented, followed by themes which emerged from analysis of both qualitative and quantitative data to address the study aims related to sources of stress and change in sources of stress over time. Finally, study findings are summarized.

Sample Characteristics

Nine parents (eight mothers and one father) from eight families whose children were hospitalized in the CVICU or PICU were each interviewed during an eight month period in 2014 and 2015. Both parents from one family participated in the study and chose to be interviewed together. Two mothers participated in data collection four to five weeks after their initial interviews, one whose child had been transferred to a medical/surgical unit two and a half weeks before the second interview, and the other whose child had been transferred out of the ICU two weeks prior, then returned to the ICU for a week and was on the medical/surgical interview again at the time of the second interview.

All participants were married, six families had one or more children in addition to the hospitalized child, and families varied in stage ranging from childbearing to launching young adults. Four families lived in the metropolitan area where the hospital is

located, three lived within 70 to 85 miles of the hospital, and one family lived more than 1200 miles away. Except for one family who lived six miles from the hospital, at least one parent for each child was staying overnight at the hospital or the nearby Ronald McDonald House (RMH) at the time of the first interview. One family that participated in a second interview had recently begun staying at the RMH, while the mother from the second family stayed at the hospital some nights and went home other nights (about 45 minutes away).

The hospitalized children varied in age (from nine days to 18 years) and reason for admission. Five were admitted for surgical intervention; of those, four were planned admissions, two immediately after birth because of prenatal diagnosis of cardiac defect. At the time of the first interview, two were sedated and on ventilators and one infant was recovering from a long period of sedation and therefore not at his baseline neurologic status; the remaining children were at their baseline neurologic status, but remained in the ICU because of airway interventions, administration of critical medications, and/or advanced monitoring.

At the time of the first interview, families had been in the CVICU or PICU for an average of ten days. The majority had been in one of these units during the entire hospitalization although two were hospitalized briefly in the neonatal intensive care unit (NICU) prior to transferring to the CVICU. Child, parent, and family demographics for each participant are described in Appendix I.

Aim 1: Sources of Stress

Content analysis of participant interviews as well as findings from the FILE, and FS³I resulted in eight themes related to sources of stress. These are presented in Table 2.

Table 2

Themes and Subthemes

Theme	Subthemes
Separation	Being apart A constant pull Family role changes Leaving the hospital Siblings at the hospital
Not knowing	Unknowns We thought we were prepared The roller coaster
Child's illness and distress	Child's distress Critical illness Future illness and health care needs
Care and caring	On the same page Listening to parents Availability of the team It depends on the nurse Continuity and fit Genuine caring for the child and family
Emotional stress	Fathers' stress I don't want to talk about it
Physical stress	Sleep Activity and nutrition Self care My husband makes sure I take care of myself
Job and financial stress	Job flexibility and benefits Financial strains
What we've been through before	We had practice Baseline stress Ongoing healthcare needs

Theme 1: Separation. Separation was identified as an important source of stress for families who had other children at home. Every respondent who had adolescent or

younger children at home reported this as their primary stressor; this includes a mother who identified two stressors as most significant. (Primary stressors are listed in Table 3.)

Table 3

Primary Source(s) of Stress Identified at Time 1

Primary source(s) of stress	Number of families
Separation	3
Unknowns	1
Separation, unknowns	1
Distance from home, availability of food	1
Child's discomfort and agitation	1
Setbacks	1

The “intrafamily strains” subscale of the FILE includes the items “increase of husband/father’s” and/or “wife/mother’s time away from family,” and was ranked highest for five of the eight families. All but two families selected these items, and a number of families reported additional strains within this category. The theme of separation consisted of five subthemes: *being apart, a constant pull, family role changes, leaving the hospital, and siblings at the hospital.*

Being apart. Participants whose first response to the question about sources of stress was about being apart described separation from their other children. Although they knew the siblings were being well taken care of, mothers were concerned about “being split” between their children in the hospital and at home, as well as the need to “juggle their schedules [at home]...and wanting to be [at the hospital] all the time.” One mother whose family lived 19 hours away from the hospital shared that this was the first time in 21 years that she didn't see her daughter on her birthday.

Mothers also described siblings’ responses to being separated from their parents; toddlers and preschoolers were more likely to have emotional displays in response to

their parents' absence. One mother shared how her three-year-old, whose infant sister had been discharged to home from the NICU three months prior to this CVICU admission, was found:

...sitting behind her bedroom door crying with her teddy bear and saying, "Mommy, Mommy." ... She's only been here [at the hospital] twice, but when she left here, she cried the whole way home, just screaming, "My mommy makes it better! Turn around! Turn around!" She was my world for three years, then she had a sibling, and now she has a sibling with complications, so it's made it even harder.

Another mother explained how her two-year-old son, whose brother had been home for only three weeks after spending two and a half months in the NICU, was more likely than his five-year-old brother to ask when his brother was coming home from the hospital. "I think [the five-year-old] understands it enough where he knows that I'm going to be here [at the hospital]." The mother of a two-year-old and 14-year old described how the two-year-old is:

...fine until she's physically there [with her parents], then it's like, "I miss you so much," and then [she gives you] a hug every time you leave the room. ... When my husband went home...he would leave and walk down the hallway, and she'd be right after him, "Daddy, you're still here; you're still here."

Adolescents' expressions of the stress of being apart were also consistent with what is expected for their developmental stage (i.e., beginning to think abstractly,

developing emotional autonomy). Describing her 14-year-old son's response, a mother explained,

...you could really see him thinking it through. He didn't really ask a lot of questions, but when he was leaving [the hospital after a visit]...he's not a big hugger usually, but he made sure he gave me like the biggest hug.

The mother of a 12-year-old, whose care has required more of his parents' attention over the past two years because of chronic illness, reported concern about her 14-year-old daughter expressing her feelings:

...when I told her we were coming here, she cried; ...on this whole journey, this was probably the most open she's been about that... It's hard enough to be fourteen, and then to compound it with having a chronically ill brother.

...yesterday she texted me a photo of her dog, and she said, "[My dog] misses you." Well, I think [her dog] and [my daughter] miss me, and I get that. I know that she does; she just has, sometimes, a harder time expressing it.

Another family, whose child had been admitted for a scheduled procedure but experienced unexpected complications, had their 7-year-old son come to the hospital to be with his family earlier than planned.

He was home and wasn't supposed to come for two more weeks, but we made a promise to him that Daddy was going to be home on Saturday, and [when his dad needed to stay] we didn't want to break his heart – because that's very stressful, when you live that far away.

Some mothers expressed the potential stress of being alone at the hospital if their husbands were unable to be there due to illness or the need to take care of the siblings at home. One mother described how her husband called one morning to say he didn't feel well, "I just had a momentary panic, like 'Oh, he's not coming today!' But then I thought, 'Oh, I can handle that.' But it was just this momentary, 'Oh my gosh! I'm going to be alone!' " This was not a source of stress for all mothers in the study. In fact, one participant expressed that, even though she had only gone home twice in the week that her infant was in the hospital, she and her husband had as much or more contact with each other as they usually did. "We talk multiple times a day and we text all day. ... I wouldn't say that's a huge factor in it because we pretty much stay in contact all day." A potential consideration may be the distance between the hospital and home (and their ability to quickly get to the hospital), as this was not a concern for a family who lived within 20 minutes of the hospital, while mothers who expressed this concern traveled two hours to get to the hospital.

The identification of separation as a significant stressor is not surprising given the priority that parents place on their children. Participants consistently described their focus on their children in various contexts throughout the interviews and while completing the instruments. Families described the value of having few visitors at the hospital and support to care for siblings so they could focus on the hospitalized child. When asked about the effect of hospitalization on mothers' ability to take care of themselves, most described how their focus on their children allowed little time for themselves in their everyday lives. One mother commented, "I don't do a whole lot of that [self care], but I

figure there's time down the road. ...they're number one, you know." Another mother explained "[Our children] are our main focus, and we do whatever we need to do to help make this an easier thing" for them. This focus was apparent in the efforts that participants made to ensure that their children's needs were met as well as in the constant pull they felt between the hospital and home.

A constant pull. Every mother in this sample who had children at home articulated feeling torn between being home and being at the hospital, regardless whether their children were toddlers, teens, or young adults.

Mother of a preschooler at home:

It makes it 100 times worse having another child; I definitely think that's the biggest pull for me right now, just because I'm so torn in her care. I don't want to hurt my other child, but I want to help this child, so I'm so in between. Then you feel guilty; like if I'm down here, I feel guilty. What if she wakes up and is scared...is it fair to my other one to be scared? ... I wish I could clone myself, because my husband's there, but he's just not emotional [even though] he tries to be very sweet with her.

Mother of a toddler and teen at home: "That's probably the most stressful thing is that your mind is still there but you're here."

Mother of a toddler and preschooler at home:

I want to be here, but then when I go home, my boys want me to stay. So that's hard having them ask me not to go. ...it's just stressful because we're not

together. My husband's trying to do everything at home; I'm wanting to be home doing it, but I want to be here, so it's a constant pull.

Mother of a teen at home:

...this is so hard, to make sure that they're both getting what they [child at home and child in the hospital] need...I want to just split in half and be with both of them and I can't, and that's a big-time stress.

Mother whose family at home included her young adult children and their toddlers: "I was here with [my daughter] and back at home the two-year-old [granddaughter] and my daughter-in-law were sick and it was just stressful there, too. More stressful probably because I wasn't there to help."

A mother who had recently spent a night at the RMH struggled with feelings that she and her husband weren't meeting their responsibility to any of their kids.

...that was really weird too. It was like we're there by ourselves, and no kids, and you feel guilty because it's like, "Okay, we have kids at home, and we have a baby in the hospital, and here we are just by ourselves."

This feeling of being torn between responsibility to their children at home and to the child in the hospital also emerged in her description of being at the hospital focused on the patient, the surgery scheduled for the next day, and the potential risks of the blood transfusion she was receiving. "And then you look at the clock and you're like, 'It's 8:00 at night! We need to call the kids at home!' "

Family role changes. Families underwent role changes as they worked together to accommodate the effects of one or both parents being at the hospital. This included

husbands taking on child care and meal preparation tasks for which they hadn't previously been responsible; grandparents, aunts, and uncles staying with their children and caring for them; and teens and young adults doing more household duties.

My parents have been helping a lot with the boys at home, and my husband has pretty much become Mr. Mom, and trying to do as much as he can. ...he's pretty much taken over at home so I can be here. ... He's not used to getting them ready in the morning, dropping them off at their places, cooking dinner.

Several participants commented that the role changes were not bad, "just different." When responding to the question on the FS³I regarding the effect of this situation on their family's usual pattern of living, almost all commented on not being at home and some mentioned the distance from home. However, despite identifying separation as a significant contributor to the family's stress, the majority responded that things hadn't changed much for their children at home because of the preparation they had made and/or support of family to maintain their routines. One mother commented that she didn't believe her children were as affected by the separation as she and her husband were, in large part because of the preparation they had made to create normalcy for their children during this planned hospitalization for their newborn.

Leaving the hospital. One or both parents in all of these families spent the majority of their time at the hospital. While they varied in their decision-making to leave for a meal or to sleep at home or RMH, conflicting feelings about leaving their child were apparent for many.

After spending a night at the RMH, one mother described: “Yes, it’s hard sleeping [at the hospital] with the beeps and stuff...but at the same time, it’s really hard to be away, too, to get the sleep.” Despite the manifestations of stress that her three-year-old at home was exhibiting, one mother said,

But you can’t leave. My mother-in-law’s like, “I don’t know why you just sit there and stare at her; it’s not affecting her,” and I truly do not believe that. I think [my daughter] very much knows when I’m there holding her hand, and I can’t leave her; that’s not me.

One mother who lived 70 miles from the hospital and had had several previous hospitalizations reported that she wouldn’t go home until her son went home. Describing a time when her husband stayed at the hospital so she could leave, she said, “I just call him ten thousand times a day anyways, so I might as well just be here. ... I don’t know, I’m probably a little overbearing, but we’ve been through so much – and I stay.”

One couple who stayed at the hospital during the day but went home at night explained,

...we’re ten minutes away, so we can call and if we need to come in, we can. ...

We can’t hold her. She’s ventilated. She’s sedated. Like there’s nothing really that we can do. So we go home every night.

The mother found it helpful to get away from the hospital but recognized that the father was “better at being here” than she was. His response was, “I don’t know whether I feel better or... You kind of feel like you’re almost doing something. It’s hard. ...she’s not interactive. You don’t really know what usefulness you are being here. It’s more the

concept.” Because they were able to attend rounds and get their questions answered by the nurse practitioners, doctors, and nurses throughout the day, these parents described “always knowing exactly what’s going on for everything.” This sense of being informed, in addition to the fact that they could call the nurse at any time, was “part of the reason we feel we don’t have to be here all the time.”

Trust in the nurse was also a factor in family’s decisions to leave the hospital.

I think one big thing that eases or makes me more stressed is her nurse – who her nurse is, who I’m leaving her with. I completely trust [nurse], but I had a nurse the other night that I couldn’t sleep for two minutes with. That makes your stay so important, if you trust that person with your child’s care; it makes a huge difference. I remember that in the NICU too; I couldn’t go home at night if I didn’t feel comfortable with the nurse.

This commitment to being with the child was apparent during data collection: parents were only interested in participating if it could be done at a time when another family member could stay with the child or when the child was sleeping. The interviews were conducted in a consultation room on the unit, and four of the interviews were interrupted and/or shortened because the participant was notified that the child had awakened and/or the parent was needed at the child’s bedside.

Siblings at the hospital. Although separation of the family was a significant source of stress for families, parents were intentional about siblings visiting the hospital, aware of how seeing their hospitalized sibling affected them.

It was a struggle at first, like I *didn't* want [my 14-year-old son] to see her with all the cords and everything and worry about it too much, but at the same time, I wanted him to see how important it was that at home, he's just doing his normal thing, making sure he's taking care of himself and helping out around home while we're not there, *because* of the situation.

A patient's 21-year-old sibling who lived 1200 miles away chose not to fly to see her sister in the weeks following her admission to the hospital. "She doesn't want to, right now, because she can't deal with seeing her sister like that. She doesn't want to see it, and she doesn't want to think about it. She just wants to think...everything's going to be okay."

One family did not bring their two-year-old into the patient's room to see her: ...because when she gets shots, she freaks out about her Band-Aids. And she calls her "my baby." She's like, "I don't want my baby to bleed," so she's very protective of her. I haven't let her see her yet because she's hooked up to a lot. I think maybe when we move up to a better floor, and she doesn't have so many cords and so many things, then we'll let her see her. But, as of right now, I feel like she's already traumatized; I don't want to make it any harder.

Factors that made it easier for siblings to see the hospitalized child included the age of the sibling and the patient's belief that she was going to get better. A mother commented on her teen daughter's response:

[My daughter] has [visited the hospital] twice, and she's usually very resistant to that. ... It's not easy for her to see him in this situation. ...she seemed very comfortable. ... So I'm thinking she's getting older, she gets it now more.

Another mother commented on her school-age daughter's willingness to let her younger brother in her room:

I think that this hospital even has made her feel more comfortable, because she would never let her brother see her sick. ... We thought it was going to be very bad, that she was going to scream and yell and say, "Get him out of here!" But she didn't. And I think that it was different [because] I think she really believes that she's going to get better.

For siblings who were appropriate to come to the hospital, parents appreciated that they could be on the unit without restriction; this helped alleviate the stress of separation. "I think that helps when you haven't seen your kid [seven-year-old sibling], because we've been gone [from home]...almost a month." This mother also appreciated that the sibling could use the playroom on one of the medical/surgical units.

That makes a difference with kids... I can only imagine if...[he] was with us all the time [on the ICU]. ...how good that would make not only the parents feel, but the other kids feel, to be able to go and be a kid and not have to worry...

One family was grateful that their two- and five-year-olds could visit their baby brother in the ICU. "...they always ask, 'Can we go see?' and it's hard to say, 'You're not allowed.' ... I see why they don't [allow siblings in the NICU], but at the same time, you kind of have to understand a family needs to be together at some point."

Theme 2: Not knowing. The stress of not knowing and/or not being prepared for changes in the child's hospital course was a primary source of stress identified by three families in this sample, and every family reported stressors that fit into one or more of the subthemes of not knowing: *unknowns*, *we thought we were prepared*, and *the roller coaster*.

Unknowns. This was the primary stressor identified by one family whose only child was in the ICU; for another mother it was one of the two most important stressors, in addition to separation from her other child. Unknowns ranged from not knowing if the child would be okay, to not knowing how soon surgery would be needed or if the child would get better or worse. (These were also unknown to the health care team because the patient's condition was changing or had significant potential to change, and the team was basing interventions on the child's changing status and response to interventions.)

One mother whose question was "Is she going to be okay?" went on to say, "I have nightmares she's going to die..." "I wish someone could say, 'Hang in there; next Friday you're going home.' But with medicine you can't – It's the unknowns." Another family reported that although they knew their child would need cardiac surgery, the fact that it was required much sooner than anticipated created stress for them, while another family's source of stress was knowing that "what they were trying to do [surgically] was complicated [and] if it didn't work, they weren't sure...what to do."

Unknowns were not unique to families whose children were in the ICU for surgical reasons. One mother whose child was admitted for respiratory failure reported, "...every day's a new day. And even though he's been moving in the right direction,

there's always that 'You never know.' ” Another mother compared the unknowns of her child's PICU admission to that of his NICU stay. “...when he was in the NICU, you pretty much know they're going to be okay, they just have to get better. ...when they come in for an illness, it's like you don't know what's going to happen.” In addition to the viral respiratory infection which had led to his admission, her child also had signs of an infection for which they had not found the source and had developed a blood clot.

We thought we were prepared. Although families experienced stress related to unknowns and not being prepared for complications, it wasn't because they hadn't tried to prepare themselves or because the health care team hadn't tried to prepare them. A mother who identified her family's primary stressor as not being prepared for “setbacks” or the “ups and downs,” stated,

We were very well educated that we needed to know that there could be roadblocks. ...[but] we were thinking, “Oh, no.” ... We weren't prepared for the stress. ... Even though mentally we should have prepared ourselves for setbacks, we've had so many setbacks in six years of her having this [illness] that we just thought, “You know what? It's going to be straightforward.”

While families were grateful that they had been told what to expect, including the possibility of changes to the plan (e.g., additional surgery, earlier surgery) based on the child's response, they still found themselves feeling unprepared. This was sometimes because they were hoping for “the best case scenario.” “We were expecting it, but we kind of hoped it wouldn't happen,” or “We knew it was a chance, but we didn't think it was very likely.” Despite preparing herself for the possibility of her child needing cardiac

catheterization, one mother described herself as being “a little bit more on edge...because it’s like, ‘Okay, I know stuff can change a lot faster,’ but they prepare you for it. That was just that initial, ‘Whoa!’ I was thinking that I had four to ten days.”

The roller coaster. The ups and downs that families experienced as their children moved through the ICU course were evident in this theme in which waiting was also prominent. This was articulated as the ups and downs of the patient’s condition as well as the family’s stress.

“Sometimes it’s just being patient and waiting, as much as it feels like waiting is stepping back. It seems like that is kind of a standard thing of the ICU is that it is a roller coaster.”

The ups and downs of how her body – the waiting for what’s going to happen with her. At first it was like...you’re waiting every second for something to change or not change, and it’s like you kind of get used to just waiting. And then you’re hopeful that it’s always going to be really good, but you realize the reality of it and the possibilities.

“I’m just waiting for it to be done.”

“Your stress really does go up and down, up and down. ... We weren't prepared for the down and then ups, and the down and then ups.”

Theme 3: Child’s illness and distress. One mother described her child’s discomfort and agitation as most stressful, while other participants spoke directly or indirectly to their child’s illness, discomfort, and distress as sources of stress for their

families. This theme was organized into the following subthemes: *child's distress*, *critical illness*, and *future illness and health care needs*.

Child's distress. A mother of a developmentally delayed 18-year-old reported, "The most stressful thing about having her in the hospital in general is when she is uncomfortable and agitated and we can't get her settled down." At the time of the interview, her child was intubated and sedated, which the mother perceived as "a lot less stressful." "It's hard seeing her intubated, but even harder seeing her not being able to breathe, and being upset about it and scared."

Another mother described the stress she experienced when a nurse was unfamiliar with the technology her child required. "It was just getting more and more stressful for [my son], and then when that happens, of course my stress level's going to go up, because any unnecessary stress on him I don't take, because that shouldn't happen."

Critical illness. The critical nature of the child's illness was a source of stress. Although a number of these children had significant histories of previous health challenges, their current illness represented the most acute episode of care that a number of them had experienced; participants' ratings of their children's current physical health status on the FS³I ranged from one to three on a scale of one to five, with five being the best health. Participants spoke of their children's current severity of illness within the context of baseline health challenges and effect on future health.

A child whose mother described her baseline health status as "below average" and her current health "way below" average was described as never having been "in the kind of precarious state that she's been in with this illness." Another mother who identified her

child's health as a source of stress reported that in his "long health journey" he had not been in a PICU for anything except occasional overnight stays after surgery. "This has been very difficult, just the stress of knowing that he was so ill with the lungs. That's always been our fear, and it happened. It came to fruition, and so that was scary." Fear related to the child's critical illness was also expressed by a mother who described that their family had just become comfortable with their infant at home prior to this elective surgery to repair a congenital heart defect. She reported, "I've seen her turn gray three times now, and it's terrifying." "She was awesome at home; she didn't have any issues. She didn't even show that she was in heart failure. ... Now it's like the world's turned upside down again."

A mother whose child underwent elective surgery following many years of serious illness described how her family's optimism in the first several days following surgery turned to stress as she experienced complications.

Last week was a really bad week. She had the bowel obstruction then she had an infection, and the bowel obstruction was not going very well. Her intestines were just falling apart, and that's where our stress really kicked in.

When rating the physical health status of their families as a whole on the FS³I, participants commented how the child's health status decreased the overall rating; family ratings were three to four, 1.4 points higher than the patient's rating on average. One mother explained,

With [our daughter] being [so sick] – obviously she’s taking up a large part of our family. It’s like yes, the rest of us are physically healthy, but I think, as a family, you all feel that for her, especially [my husband and me].

There were two exceptions in which the patient’s health did not decrease the overall family health rating: a mother whose child was alert, active, and happy (and in the ICU for monitoring due to an externalized ventriculoperitoneal shunt) rated her own physical health two and her son’s three; and another mother rated her physical health as three, the same as her daughter’s (the patient).

The “illness & family care strains” subscale of the FILE was ranked second highest on average among families in this sample. Every family selected events in this subscale as contributors to the pile-up of life events. Two families only selected the item “child became seriously ill or injured,” while all other families selected a number of additional items.

Future illness and health care needs. Participants also talked about their children’s illness and future health care needs. Some identified that their child’s health would be the same or better after discharge from the hospital while others were concerned about the potential for increased care needs and the effects that may have on their families.

...still I don’t know how it’s going to affect our future, because I just don’t know how she’s going to come out of this...it’s also scary because we don’t know if we’re going to get to go [on vacation] this year or if she’s going to go home on

oxygen, so that part's hard. Or can I even go back to work because can she go to daycare?

One mother selected the item on the FILE "increased difficulty managing chronically ill or disabled member," specifically stating that it was in anticipation of her child's long recovery. "I've been told this is going to be a long process getting her back to healthy. ... We don't know what it's going to look like, but she will be needing more care for a while at least." A mother who expressed significant fear about her child's current status and prognosis was concerned about taking her home. "I don't want her coming home like that. [crying] Obviously they won't let us. I don't want to take her home and go backwards either."

Theme 4: Care and caring. The majority of participants expressed overwhelming confidence in the care and caring of the team and did not identify this as a source of stress, but as helpful in alleviating or preventing stress. Belief that their child was in the right place (the ICU and/or this particular hospital) was a source of comfort to families; several families had specifically chosen this hospital for their child's care and stated that they wouldn't take their child elsewhere. A mother who had traveled 1200 miles to bring her child to this hospital expressed,

I think that being here is way different than the hospitals we have at home. This hospital is amazing, and even though we've had some setbacks, we feel like this is a blessing; we've been brought here for a reason.

Families expressed gratitude for the ICU and recognition that it was the best place to be, given their child's condition. The overall tone of all but two of the initial interviews

was extremely positive in regard to the care and how it was provided, and one of the mothers whose interview wasn't as positive concluded her comments with "...as a whole, I think our experience has been wonderful." Others' comments were consistent with this statement made by one participant, "The nurses here have been so awesome, the doctors, all the staff. I have absolutely zero complaints and much praise for everybody that's dealt with her care here."

However, some sources of stress emerged in families' perceptions of the care and how it was provided. Both stressors and stress alleviators will be described in relation to these themes since the families' discussion of these factors as stress alleviators implies that they perceived them as potential sources of stress although their personal experience up to the time of the interview had been positive. Additionally, in some cases families contrasted their current positive experience with their experience in other settings in which they had experienced these as sources of stress. Subthemes included: *on the same page*, *listening to parents*, *availability of the team*, *it depends on the nurse*, *continuity and fit*, and *genuine caring for the child and family*.

On the same page. Families commented on the importance of the team being on the same page and not sending mixed messages; some of these families had previous hospitalizations as points of comparison and one had no previous hospital experience.

A mother of a newborn stated:

We haven't gotten any mixed messages on her care, what's to be expected, or anything like that – or any leading us in a false sense of direction for hope. It's been very matter of fact and presented in a caring way, but just the facts.

Another mother whose child had had multiple hospitalizations and clinic visits due to a chronic illness commented several times that “everybody’s on the same page”; this was in contrast to her experience at the hospital and clinics in her home state. She addressed this in relation to nurses being able to address alarms and patient requests even if they weren’t assigned to that patient, and to physician teams who continued the plan of care when they covered for each other.

I think that helps a lot, you know, the stress level with parents, knowing that every single person is always going to be on the same page: how they do the rounding, involving the parents. I think that helps eliminate a lot and makes people feel comfortable just knowing that everybody knows what is going on with that person.

This was not the experience of a third participant who expressed concerns about rotation of resident and attending physicians and the frequent need to re-tell her story.

That’s another hard thing, is with the doctors changing. The first doctor was like, “It’s not a blood clot; don’t worry about it. Cancel the ultrasound.” And then yesterday, the new doctor’s like, “Why haven’t you ultrasounded his leg?” ... So that sort of communication, too, has been stressful because it’s like I feel like I have to re-tell the new doctor.

Listening to parents. This subtheme was reflected in interviews with three participants: one for whom this contributed to her stress during this ICU stay and two who contrasted their current positive experience to previous experiences at other hospitals and clinics.

I've had a couple of issues with him here now, like me telling the doctor that there's something wrong, [and he responded] "No, that's fine; it's fine." And then three days later, "Yep, that's wrong." So, it's been frustrating. ... Part of me is like, "You're the expert; you should know." So it's like "I'm not going to question you," but at the same time, I know this isn't normal.

Her advice was:

...listening to parents more. I told them, "He's really pale," and I got, "He might just be a pale kid." I'm like, "I have known him for three months, and you've just met him today. I think I know what my kid looks like." And I told them, "This isn't what he looks like. He's very dehydrated. I can see it." And just not listening.

Given the lack of success in her efforts to be heard by the team, this mother articulated the need for nurses to advocate on the child's and family's behalf.

Communication is good between the nurses and the doctors, but I've had some nurses that are almost – I don't want to use the word "scared" – but apprehensive to go to the doctor. Because when he was coming down with the infection, I'm like, "He's just really pale and sweaty," and the nurse would be like, "Yeah, I agree." And I'm like, "Well, you need to voice that because they're not listening to me; maybe they'll listen to you."

She needed from the nurses, "More advocating for the patient because they're the ones that see them. The doctor sees them twice a day for five minutes."

Another mother reported that the ICU nurses:

...listen really well, or they might pick up on something or I might ask them,

“What do you think about this?” The nurses here are great. ... I mean the doctors are, too, but you work closer with the nurses and they’re really great. They listen.

This was very different than her perception of the multiple providers who had seen her child in the prior four months and hadn’t taken seriously the infection that led to this hospitalization. “...we can’t really be mad at anybody. We’re irritated, yes. He had the scabs for four months, and it took everybody four months to listen to us, and then we’ve been here for almost two weeks.” Because of this, she rated higher her response to the FS³I question regarding “how much your family is bothered by this situation,” rating it as four. She also expressed similar concern about her child’s primary care provider listening to her and her husband in general. “I do feel like [his primary care provider] thinks I’m over paranoid, but I’ve never been wrong. I’ve even told a resident here that when he wasn’t listening to me. I said, ‘I’ve never been wrong.’ ”

A third mother expressed her appreciation for the way the team solicited her input, from the time of clinic consultation through her ICU stay.

Something else that I think that they help with is they want your recommendations. They don't want to go by textbook. So say, every patient is different, which we've heard that for six years, but when you try to bring that to a doctor's attention on what you think about your own kid, half the time they would look at you like “That's not possible.” ... It's just wonderful to feel like they know that this is what is going on with my kid.

Later in the interview, this mother commented, “It's been a long time since we've felt like somebody really knew our kid.”

This was in contrast to the mother of an infant who had been hospitalized in the NICU for two and a half months, then readmitted to the PICU three weeks later. Her situation highlighted the importance of two-way communication, not just one-way information-sharing. Although she reported, “They're at least telling me what they're doing,” it was tempered with, “Not that I've always agreed with it.” When describing interactions between her family and the staff and providers, she stated:

I think it's almost made it harder because we had *such* a good experience in the NICU, that I guess I expected that everywhere, and it's a little different here. It's just not as personal. And I guess I've had a little bit of problems with communication, like me telling someone and then it has to go through four people to get to the doctor, and getting my point across. Where, in the NICU, I got to sit down with the doctor and the nurse and everyone every day and talk about everything, ask all my questions. Where here, it's like I just kind of sit back and listen to rounds, which is nice, but it just doesn't seem like I'm as involved.

Availability of the team. Families identified the ready availability of the team as a stress alleviator. This included nurses, nurse practitioners, residents, and attending physicians. One mother stated, “...you always have somebody to communicate with. You don't have to wait an hour for a resident or somebody. There's somebody always on this floor that can be right here.” This was similar to other families' reports, which also

addressed the availability of the nurses by phone when parents needed to be away from the hospital.

A mother whose child had had several spells requiring quick recognition and intervention articulated how staff availability made “a huge difference” in her stress level. This included having a one-to-one nurse-to-patient ratio and her child’s assigned nurse being inside the room or in the alcove outside the room, as well as the doctors, nurse practitioners, and nurses sitting at the desk or team members walking through the halls; knowing they were there made her feel safer.

It depends on the nurse. The nurses’ knowledge and competence were addressed by every family, and in an overwhelmingly positive way by the large majority of participants. Nurses were described as “so awesome” and “fabulous,” and participants commented on being impressed by their knowledge, competence, and confidence. The mother of a child with multiple admissions to another hospital described how she felt comfortable leaving her child in the nurses’ care.

...for six years, neither one of us has ever left [our daughter] at the hospital by herself. We've always been in the building. We actually left and went out to a restaurant [last week]. So that says a lot. In six years – and being as far as we are from home – we felt that comfortable leaving our child here. ... Because we know that she's in the right place, that the nurses here, they're very confident; not just the doctors, but the nurses.

Others articulated how it depends on the nurse. "...the nurses are the biggest stress relief or stressor...I think the nursing care makes a huge, huge difference." One mother who described the care as "fabulous" qualified her answer with:

[How we work with the staff] depends on the nurse...for the most part, that's been really good. But there have been a couple of nurses that my stress level went up to the ceiling, because they didn't seem to know the [BiPAP] equipment... And so one night, we did get a new nurse. And then one admirably said she didn't know how to access his port...so I asked for a chemo nurse...to change the port needle.

Mothers also commented on the variation in skill level of different nurses and nursing assistants. "It's just amazing as I watch people, and it's any profession. There are people that you're just like, 'Wow, you've got it,' and others you're like, 'I don't know if you've got this.'" Describing similar observations of variation in skill level and professionalism, another mother articulated, "I'm just like, 'How is this happening?' And then the next day I get people like [nurse], who are just above and beyond to me."

Continuity and fit. Continuity or lack thereof factored into family's stress, as one mother described.

Sometimes you're used to one nurse, and then you get somebody else, and then you start all over again. And that can be a little stressful, especially if they're not jiving with [my son]. [He's] a creature of habit, and he likes to have the same faces.

This applied not only to continuity in the assigned nurse, but in the continuity that different nurses provided by doing things the same way.

I really appreciate how the nurses prepare the child. And they ask, “What can we do to make the situation better?” That's something that I've never experienced.

And if you tell the next nurse, they will come behind and do the same thing, so it's a repetitive thing. ... It's not like they're stuck in their own ways. “We're going to do it this way or no way.” They're willing to take what the other nurse did that works with that patient.

Some participants commented on the importance of the nurse's style or personality being a good fit for the child and family. “There are some nurses that gel with your kid and gel with the parents. ...if they're not getting through to [my daughter] and they're not helping her, then you might as well not even send that person over.” However, although differences in nurses' style of providing care were acknowledged, this was not always a source of stress.

It's a good balance because some people are really personable and some people are very focused on the task. And it's like both things make you feel really comfortable...everybody has their own little way of doing everything, but it all works. It's comfortable either way.

Genuine caring for the child and family. Families experienced stress when they perceived that staff didn't truly care for their child or family and their stress was alleviated when genuine caring was demonstrated.

Definitely the people involved make a huge contribution to the stress level while you're here. ... You can tell the nurses that it's their job, and you can tell the nurses that really care about your child. That definitely heightens or lowers your stress level.

A nurse who she perceived as caring was always present in or directly outside her room even when the mother was taking care of her daughter. "You can tell, she's just sweet to my daughter, just talking to her, and she's not just another job; she's a person." This mother also described the security of knowing that her primary cardiologist was in contact with her every day. "She loves my daughter; she's not just a patient, she's part of her life too. That helps. This journey, I think, would be a lot harder without her."

Several participants acknowledged the connection they felt to the staff. In addition to their competence, staff were described as "kind," "courteous," "eager to help," and "welcoming." Others expressed, "We love the staff in the CVICU." "I feel like this hospital is our family now." Participants appreciated the care provided for the family as well as the patient. "[The nurses have] been great...I'm like, 'Well, I know we're in the ICU, but they are really good! On both levels, the patient level and the family level.' "

I appreciate the fact that the nurses know when you need a break. ... They can tell by your facial expressions when you're stressed out and you need to go. They tell you, "Take a break." Our nurse made my husband and me...leave [last week]. "Get out of the building, go get something to eat."

One mother appreciated that when her child was critically ill and family members came to the hospital to provide support, they were allowed to have more than two people in the room.

As long as we were being quiet and just sitting there, that really made a difference, to be able to know that, they're not going to sit there and say, "Okay, two people. That's the rule; that's the law," as long as [our daughter] was okay. ... I think that makes a world of difference when you have a sick kid. And I appreciate that for myself, and I really appreciate that they're letting other people do that, because, you know, family makes you feel better.

Theme 5: Emotional stress. Emotional stress was specifically addressed by the majority of families in this sample. Reasons for emotional stress ranged from general (i.e., having a child in the ICU, unknowns) to specific (i.e., nervousness about upcoming surgery, watching the child undergo procedures or seeing the child's incision). One mother described the ICU experience as "overwhelming." One couple (first-time parents) described having more emotional stress than they anticipated because of the immediate connection they felt to their child. "It's weird for us because you know it's very emotional... We're not overly emotional people, so it's kind of been difficult. Or it's just different...for us..." [father]. "All of a sudden we have a lot of emotions" [mother].

While descriptions of emotional stress were typically those of the parents, one mother described her daughter's emotional stress in relation to having her infant sibling in the ICU:

...my daughter...even uses the words ...”You’re stressing me! You’re stressing me!” which scares me that she’s hearing that way too much. It’s hard. Last night, when I went home...she kept holding my face, [saying] “I’m here, Mommy, I’m here.” She’s three, but you’d swear she’s acting like she’s 13. ...and I don’t want her to hold that. But I can definitely see it on her.

Subthemes included *fathers’ stress* and *I don’t want to talk about it*.

Fathers’ stress. Mothers commented on the stress their husbands were under and ways that their sources and expressions of stress differed. One mother described her husband as “under a lot of stress.” “I think he’s just exhausted” as a result of driving 70 miles to and from the hospital each day, taking their daughter to dance, “keeping the home fires burning,” and “being the financial means to the family.”

Differences were also expressed in how fathers responded to the stress; for some fathers that response was anger at seeing their children hurting. One participant, whose child had been admitted with a serious infection after several months of having their concerns disregarded by his primary doctor, described her husband as “very crabby. He won’t even talk to the doctors because he’s afraid he’s going to blow up. And you can’t blame him.” She described his difficulty seeing his son in the ICU for two weeks, “the toll it takes on him going back and forth,” and supporting his wife; “sometimes I cry kind of easy, so that doesn’t help.” Another described her husband as “dealing with it differently.”

He gets mad a lot. He gets angry if he sees her in pain [like when she had to be poked four times for blood] ... He deals with it more aggressively, and I cry. ...

His way is just not being there. Whereas, I just don't care how much it hurts me, I have to be there. We just handle it differently. He can't stay here; he has too much anxiety. When he is here, he has to be outside, so I'm like, "Well, why are you here?" We look at it differently. I don't know if that's a dad versus a mom thing or it's also personality.

A mother whose child had had multiple previous hospitalizations compared this to previous experiences:

[This hospitalization] has been a little bit harder on me. ... Seeing the incision that she has, and that being open, I've had to really be strong, because my husband has not been able to [look at the open wound]. I've had to put my feelings aside and suck it up and not cry.

One mother laughingly pointed out a difference in what her husband considered stressful and could accommodate while their child was critically ill. When told about his other daughter's new boyfriend, something that the rest of the family considered "a pleasant distraction," he became upset because "in his mind it was like, 'I'm so stressed about [our daughter, the patient] and you're going to throw at me that there's a guy you like?!' "

While most participants described things they perceived to be difficult for their husbands, one wife reported that her husband was "handling it a little better – or much better – than me, but it still takes a toll obviously." When responding to the question about the mental health of each family member on the FS³I, four mothers rated themselves lower than their husbands, two rated themselves the same as their husbands,

and one mom rated her husband lower than herself. The couple that participated in data collection together gave themselves and each other the same rating when completing the FS³I individually.

I don't want to talk about it. Talking to friends and family members about their child's condition was a source of stress for some families, sometimes because of how others responded to the information they shared.

We have a Care Pages set up...and then when people still want to call and ask, we just say, "We've thrown out everything we really feel like talking about on the day, and we don't really want to talk to anyone else about the medical situation."
... We want to talk about it when it's good but we don't want to talk about when it's bad, so you kind of have to take both. ... It's semi-therapeutic to talk about but semi isn't. It kind of just becomes this perpetual conversation...

His wife commented on differences between their families in this regard. Because her family was more open to not talking about it if she didn't feel like it, she was less stressed by this; he agreed with her assessment that his need to please people "adds a little bit more stress to you than probably comfort."

Another mother told about communication with her mother-in-law who doesn't use text messaging, so she has to call her for updates. "...then it's a half-hour conversation, and then she asks me fifty thousand medical questions. And I get tired of explaining it, to be honest." Because she perceived her mother and her in-laws as "a bunch of negative Nellies," "there were a couple days up here I didn't talk to anybody. I

just didn't want to. I finally told them all, 'I'm just sick of listening to you all.' So I quit talking." Her mother-in-law's concerns added to her stress.

...she's starting to try to micromanage *everything*. That causes a lot of strain on my end, because she's like, "I worry about you guys paying daycare, and I worry about this. And I worry about your boss firing you." ...she's gotten so bad that I finally did kind of have to jump in and tell her that those aren't her problems to worry about.

Theme 6: Physical stress. Physical stress was mentioned by a number of families, including subthemes of *sleep, activity and nutrition, self care, and my husband makes sure I take care of myself.*

Sleep. Lack of sleep was the primary factor contributing to physical stress. Reasons for lack of sleep ranged from pumping breast milk to concern for the child, "waking up wondering if he's okay." One mother recalled her experience after previous admissions. "I can live on very little sleep, but it's going to take its toll. A lot of times, after we've left here, I've gotten really, really sick. *Really* sick. Like one time I needed two bags of IV fluids."

One mother was only able to sleep when nurses she trusted were caring for her child. "I completely trust [nurse #1], but I had a nurse [#2] the other night that I couldn't sleep for two minutes with." She later commented:

I couldn't sleep because [nurse #2] wouldn't stay in the room. You can tell, like when I peek [out from the family area in the patient's room] – There's [nurse #3]; he's here and wonderful, the whole time. Any time the first few nights I'd peek,

and he's always just humming and dancing around her, and you could just see he loves what he's doing. [Crying] So I could sleep.

Activity and nutrition. Other factors affecting parents' physical stress included inactivity and not eating normal meals. While completing the "physical health" section of the FS³I, some participants explained that they rated themselves lower because of being at the hospital "not doing anything" and eating out of the vending machine.

For one mother, food was part of her answer to the initial interview question about their family's stress related to having her child in the hospital. In addition to the stress of being in an ICU and not very close to home, she stated:

...just trying to figure out what to eat, I think, is probably one of the biggest stressors... How much can you eat out of the cafeteria or order in before you just can't do it anymore? It's all gross. I don't want to eat anything.

Cost was another reason it was difficult to eat all her meals at the hospital.

Self care. Mothers reported not having time for self-care, which wasn't unique to this situation. For some this was compounded in the hospital, but for others their ability to take care of themselves was the same or even better than usual. A mother who had become the primary caregiver for her pre-teen in recent months stated, "I'm probably actually taking care of myself better here than there, because the nurses are his caregivers, and so I can sit back and relax a little bit more."

One mother expressed that she didn't have time to take care of herself because of multiple hospitalizations and ongoing care needs of her child with special health care needs (CSHCN). She rated her physical health as two and her mental health as three on

the FS³I, reporting “big anxiety issues” and “PTSD” due to watching her child self-extubate at another hospital emergency department, as well as a recently healed broken foot for which she didn’t have time to get physical therapy. She had a prescription for anti-anxiety medications which she took rarely. When asked if she had been able to obtain counseling to help work through the anxiety and PTSD, she responded, “No, I’m always here. I don’t have any time for myself. I mean, realistically, I’m either at work or I’m with [my son].”

Although another mother acknowledged that she was not sleeping, “overeating, under eating, sitting there eating chocolate when she’s sleeping,” she described her time to take care of herself as the same as always. “There’s just more demand here than there is at home.” She contrasted herself with her husband: “I think my husband takes care of himself fine. The only thing [different] is his tobacco; I think he constantly has a chew in his mouth.”

My husband makes sure I take care of myself. Mothers talked about the role their husbands played in making sure they took care of themselves. The mother of a newborn with prenatally diagnosed congenital heart disease described her husband as her “voice of reason.”

That was one thing we had talked about...that he was probably going to have to encourage me to leave and get sleep because I knew that I’m just going to want to be there and hold her and watch her all the time. And I knew that I needed that – somebody to just tell me to...go get some sleep, just so I stay healthy.

She also described how her husband's ability to predict her responses was supportive in stressful situations. Other husbands reminded their wives to take a nap or eat, or sent someone to the hospital to stay with the patient so she could get out.

Theme 7: Job and financial stress. Overall, families in this sample reported more positives regarding job and financial aspects than they did negatives; however, responses on the FILE and interview responses revealed some sources of stress. Both stressors and alleviators will be discussed in this theme; although many were not sources of stress for participants in this sample, they were recognized as potential stressors for ICU families. Subthemes include *job flexibility and benefits* and *financial strains*.

Job flexibility and benefits. Participants in this sample described the value of having jobs with good benefits and flexibility, as this helped prevent stress. Fathers were able to get away from work to spend time at the hospital or had taken leaves of absence. The father of the family that lived 1200 miles away from the hospital had recently gone into business with his father, which allowed him to come to the hospital and stay longer than anticipated when his child experienced complications. Another father hadn't worked since his son came in to the hospital; "...the kids come first, and he has a fabulous employer who understands that."

One father had started a new job the week after receiving his daughter's prenatal diagnosis of complex congenital heart disease. Not only was he grateful that the new job provided him flexibility to "come and go as I need" from the hospital, but his wife commented on how much he liked the job, "so what we thought was going to be a stressor is actually a huge comfort." Another mother expressed feeling fortunate for her

job with short-term and long-term disability and her husband's job that provided family medical leave and accumulated sick time; in addition, they had subcontractors who could keep their small business running while they were at the hospital with their infant. One mother shared how her husband had recently been granted his request to move to a different division in his company.

So he's now in this interim space, which has actually been a blessing because [he] hasn't been given his new assignment yet, so...he goes in, just checks in on a few things and leaves... He's kind of glad right now that he doesn't have a lot going on.

Families were also grateful for the financial stability that good jobs and benefits offered and therefore prevented financial concerns from contributing to the stress of this situation. "Neither one of our pay has changed. I'm on disability. So I feel like that's another thing that would be a big stressor for families...we're kind of lucky in that aspect."

Financial strains. While job flexibility and benefits were helpful, families still experienced financial strains associated with their child's hospitalization, sometimes compounding pre-existing financial concerns. Only one mother spoke about financial strains (related to food, parking, and daycare) in the initial interview, but several families reported them on the FILE.

Items from the "finance and business strains" category were not the largest contributors to the total FILE score for most families; however, two families (both in the family stage of "launching") had higher scores in this subscale. For one of these families,

this subscale was the second largest contributor to the total score; this family also had the highest overall FILE score and was the only family in this sample whose FILE score was categorized as high at the time of data collection compared to normative data. Of their total 210 points in this subcategory, 60 had been incurred since the child was admitted to the hospital (“took out a loan or refinanced a loan to cover increased expenses” and “increased financial debts due to over-use of credit cards”). For the other family with a high score in this subscale, the increase in financial strain was due to educational expenses for several children and this subscore was relatively low in relation to their other subscores.

Theme 8: What we’ve been through before. Families varied considerably in the amount and sources of baseline stress. This was apparent in scores on the FILE as well as interview responses. Subthemes included: *we had practice*, *baseline stress*, and *ongoing health care needs*.

We had practice. The majority of families had experienced a similar stressor prior to this hospitalization; many had experienced several prior hospitalizations, some in an ICU. Of these, all except one rated their families four or five in response to the question on the FS³I, “How successful was your family in dealing with this situation in the past?”

One mother whose child had recently been discharged from the NICU prior to this PICU admission stated:

We kind of had practice, although I didn’t stay at the hospital when he was in the NICU...I came down here every day, I had to have people watch the kids, they

went to my parents on the weekends... [This PICU admission] was a huge change, but we had already done it before, so it wasn't too hard to get back into it.

Another family had already made changes in their routines as a result of their son needing additional care at home, including the mother quitting her job to care for him.

[My husband and daughter] are the ones who go out and do things, and [my son] and I are home, and we have our routine, too. ... So in some respects, this [ICU admission] really hasn't affected it that much, because it's [my son] and I doing our thing, and [my husband and daughter] doing their thing—just a little farther from home.

Given their previous experience with hospitalization, this mother packed a bag when they went to the hospital for this unplanned admission; “I got ready to move in because I knew that was the deal.”

Baseline stress. Responses on the FILE provided significant insight into the baseline stress that families were under, both in their report of items on the scale and in the discussion during or following its completion which often generated additional information about the foundation of stress that was in place prior to this illness and hospitalization. Families indicated that some items on the FILE had occurred since the child had been admitted to the ICU, but for many, responses represented baseline family stress. Total scores and subscores for each family are shown in Table J1, representing the time prior to this hospitalization or onset of this episode of care.

Four families' total scores placed them in the low stress category at baseline per normative data; the remaining four families' scores were moderate. Although two

families had only one child, their total scores were not similar (one was low, the other moderate). The two families in the “launching” stage had the highest total scores. There were no other apparent patterns based on family stage or structure.

The mean score on the “intrafamily strains” subscale was highest for the group, although the second highest mean score was in “work-family transitions and strains” and more individual families’ highest subscores were in this category (five families compared to three families with highest scores in “intrafamily strains”). Few families reported items in the categories of “marital strains” or “losses,” and none reported items in the “family legal violations” category.

Completion of the FILE confirmed for some families the level of baseline stress they were feeling. A couple who commented that they had “only three yes’s on the whole thing” said, “[Completing the FILE] more just made me realize how lucky we are going through it. ... That kind of confirms what we were thinking, that this could be a lot harder.” Another mother, whose total score placed her family in the moderate category, summarized, “We’re all kind of feeling like none of us can catch a break right now.” She reported stressors from a variety of sources including: the death of her father-in-law, her mother-in-law’s difficulty coping and the effect on the rest of the family, a recent move to a new town and not having any friends, and the post-traumatic stress disorder she experienced from events during a previous emergency department visit.

The mother whose score was second highest included in her list of family members her husband, five children, three grandchildren, and one daughter-in-law – all of whom were living at the family home or transitioning in and out. She described her

family's "stressful year" with multiple transitions in and out of college, jobs, and homes, in addition to health issues. "We had a very stressful December, too, because of additional things that didn't come up in the survey..." This mother went on to describe the happenings in her household during a single month, including eye surgery for one child (the current ICU patient), birth of a granddaughter who stayed with them for several weeks after delivery, hip surgery for a young adult daughter who lives with her parents, "stomach virus" in a granddaughter (whose mother had hip surgery), complications after the child's eye surgery requiring every other day clinic visits for three weeks, and her own knee surgery. Despite these multiple health challenges, work-family transitions made the largest contribution to their total FILE score; this was due to activities of launching adolescents and young adults as well as the complexities of exploring the best options for transitioning her child with special needs (the patient).

It's been actually a stressful time for me because just trying to figure out her future. I've been looking at group homes for like a year-and-a-half...trying to figure out how you choose one. ...but there's no openings anywhere. And so we're looking at increasing our in-home supports, just to start to transition her to a place where she's taken care of more by outside people and less by me. I'm also ready to lighten the burden of managing. ... I've been very, very much the primary person taking care of her.

This topic of transition and seeking the best care was common in this sample of families of children with ongoing health care needs.

Ongoing health care needs. While the majority of stressors identified on the FILE were not directly related to the present hospitalization, many were part of the larger context of the child's special health care needs. One example is the family with the highest total score, who had experienced 21 hospitalizations over the previous 20 months. Items from several subscales contributed to their total FILE score, the most significant being intrafamily strains, none of which were new during this hospitalization. This mother's perception of her family's success in dealing with a similar concern in the past was one (low), unlike other participants who rated their families four or five on this question on the FS³I.

Several mothers had made job changes to accommodate their children's special needs. One had quit her job 18 months earlier to take care of her pre-teen son who required total care due to a chronic illness. Another was in the process of selling her business to stay home with her three children, because her infant who had recently been discharged from the NICU was going to "require a lot more work" and she didn't think he could go to daycare while requiring feeding through his gastrostomy tube. A third mother had recently moved to a new city and obtained a new position for which she had stated in her job interviews that her child's special needs would require the ability to be gone if he needed medical care. Two mothers were on disability due to recent pregnancy and had made accommodations to be away from work in anticipation of the birth of a child with a congenital heart defect. Another mother had been on leave since her child's birth five months earlier, to avoid exposing her to infection at a daycare center prior to

her heart repair. She was facing the potential decision not to return to work given her child's status after surgery.

...now I'm even more scared, if they say that this is so touchy, to put her back in a daycare center. So I don't know if I'll even go back. But I do carry our insurance, and I have awesome insurance, so that's hard to give up.

Ongoing health concerns were sources of stress for six of the eight families. Only two families had had no previous hospitalizations; however, these were parents whose newborns had been admitted to the CVICU for management of congenital heart defects and would require significant care in the future. Previous hospitalizations are described in Table 4.

Table 4

Previous Hospitalizations and PICU Admissions

Family	Previous hospitalizations (hospital LOS)	Previous PICU admissions
1	None	None
2	None	None
3	4 years ago (16 days) 1 year ago (5-6 days) 7 months ago (5-6 days)	3 times (1 night after each surgery)
4	NICU 3 weeks ago (2.5 months)	None
5	7 admissions in past 8 months NICU 15 months ago (20 days)	2-3 times
6	12 years ago (6 weeks) Multiple hospitalizations (3-10 days each) 8 years ago – most recent hospitalization	3 times (1-2 days each time)
7	21 hospitalizations in past 20 months	None
8	NICU 3 months ago (7 weeks)	None

Note. LOS: length of stay.

Participants talked about the stress associated with having a CSHCN and the lack of understanding they had experienced from health care providers and others. One mother articulated:

I had no idea that there was so much stress in caregiving. ...[for the past eight months] we've been dropped on this different planet. You have this healthy boy who played baseball and every sport in the world, and could do anything, and now he's like your infant again. And so that is a whole different world. I just can't explain that to people who aren't in this place. But it really opens your eyes to the people who have been there before you.

Another mother felt that her child's primary care clinic providers didn't understand all that she was dealing with.

[My clinic] kind of beats me up about [my son's] weight...and I tell them, "[My specialist] is not concerned." ...I'm probably just not going to be as worried about it. ... One day [my pediatrician's nurse was] like, "[Your son] really needs his fingernails clipped!" So that kind of makes you feel bad as a mom, you know? ... I finally just said to her, "I need to pick my battles, because I don't think you understand how much that we're actually in and out of [the hospital] ... You see us here, but I don't think you realize how much we're actually in the [hospital or specialty clinic] where you don't know." And I don't think she gets half of the stress of [it] ... Any time you have a kid with a shunt, there's an extra stress added, because that's a device in his brain.

When families were grouped according to three phases of chronic illness (crisis, chronic, and terminal) which interface with individual and family life cycles described by Rolland (1997), some potential commonalities emerged in how families in each group talked about their stress. Table 5 categorizes families according to the phases of illness and potential commonalities in the overall tone of their interviews as they discussed the stress associated with this acute illness within the context of previous and future health challenges. Since the point in the life cycle at which the chronic illness occurs not only affects the way that the family responds to the illness, but also influences the consequences that the illness has for the family's future development (Rolland, 1997), family stage is also indicated in situations where it was deemed a particularly important consideration.

Table 5

Phase in Illness Crisis and Relationship to the Acute Illness/PICU Hospitalization

This illness represented	For these families	Common Themes Related to Phase in Chronic Illness	Sources of stress, overall tone of interviews describing acute event in relation to overall chronic illness
Crisis: initial adjustment period	#1, 2	Neonates with prenatal diagnosis of complex cardiac defects; not thinking beyond crisis of today, but many unknowns about how this affects the future and family adjustment	#1: not thinking beyond crisis of today, but rated highest (5) effect on family's future on FS ³ I; family life cycle: new parents #2 unknowns because of minute-to-minute course changes; no discussion of future health challenges or their effect on family
Chronic: "long haul" with hope for improvement over time*	#3, 5	Diagnosed within 1 to 3 years; have adjusted to living with chronic illness with episodes of acute illness (e.g., this hospitalization); anticipate improvement over time	#3 stressful that he is sick enough to be in ICU, but used to this; some things better in ICU than home #5 stressful that he has to be in the ICU, but used to this; illness acuity not very high right now (in ICU for externalized shunt)
Chronic: "long haul" with no hope for improvement over time*	#6	Adolescent with severe chronic illness and developmental delay since infancy; do not anticipate improvement over time	#6 primary stress identified: child's agitation and distress, but primary focus of interview related to transitioning her home care from mom as primary manager, other family life transitions
Between crisis and chronic	#4, 7, 8	#4: acute illness in baby with NICU history who mom thought would do fine; is this beginning of more problems vs. single event? #7: chronic illness in school-age child diagnosed 6 years ago #8 planned surgery in baby with congenital heart defect and NICU history Overall theme: episode of illness that challenged their understanding of what to anticipate and thus their adjustment to the initial diagnosis	#4 getting through this acute illness; incongruent responses, i.e., don't anticipate problems after recovery from this acute illness, but making career adjustments to accommodate child with special needs #7 multiple family life events (FILE subscales) at baseline; new treatment this hospitalization led to new adjustment period understanding how this will affect her health and their family; FS ³ I success in dealing with previous situation was low (1) #8 mom thought was doing well at home but required cardiac repair; question if/how this changes everything in the future (T1); shift to thinking of her child as chronic; yes to FILE question re: chronic care; interview focus on "looking at her in bigger picture of her illness course/life" (T2)

Note. "Hope for improvement over time" is not in Rolland's model; added as important distinction for families in this study. NICU: neonatal intensive care unit; T1: Time 1; T2: Time 2.

Aim 2: Change in Sources of Stress Over Time

Findings related to this aim emerged from the initial data collection with all eight participants and from the second phase of data collection conducted with two participants who met criteria to participate in the second interview. Data were analyzed in two primary ways: 1) comparing sources of stress discussed in interviews at Time 2 to themes that emerged from Time 1 data, and 2) identifying themes about changes in source of stress from data collected at both time points.

Comparison of stress sources. The primary source of stress had changed for each family that participated at Time 2, and of the themes that emerged from Time 1, *care and caring* contained the stressors that made the most important contribution to family stress at Time 2. A number of other themes from Time 1 were also supported by data from Time 2 although some factors that had been recognized as important sources of stress earlier in the stay had a decreased role in the overall stress or were now stress alleviators, while others increased in relative importance in the families' stress experience. The comparison is presented in Appendix K.

Change in primary sources of stress. One family for whom "setbacks" in the child's condition (*not knowing* theme) had been the primary source of stress no longer considered this an important stressor. Instead, they were most stressed by the physician teams not being on the same page (*care and caring* theme), which was very different than their experience at Time 1 when they had specifically identified this as a stress alleviator. The mother attributed this to differences in who provided physician coverage on the ICU compared to the general care unit to which her child had been transferred two and a half

weeks prior to the second interview. "...downstairs [in the ICU] they were more on [the surgeon's] page. Up here I don't feel like they're on his page." The fundamental reason that this was a significant source of stress is explained within the new preliminary subtheme, *considering the child's entire picture*.

The other family whose primary sources of stress at Time 1 were "being split" between the child in the hospital and the one at home (*separation* theme) and unknowns (*not knowing* theme) still identified these as contributors to stress, but articulated ways in which they played a smaller role in their overall stress at Time 2. Now a primary concern was physicians who didn't interact with the family or plan care in a way that acknowledged the larger picture of the child's life and illness course.

Separation. While the stress of separation was discussed at Time 2, the effect on both parents and siblings was less than that described at Time 1. Siblings had spent more time at the hospital in the intervening weeks and families had found additional ways to integrate them into the care of the child and the routine of being in the hospital.

A 3-year-old sibling who had not been in the patient's room while the patient was critically ill had now been at the hospital several times.

...she comes right up here and kisses her and plays with her, and she loves it. She doesn't notice the tubes any more. At first she actually noticed the little bruises on her legs and was like, "Why does she have dots?" But now she's fine.

When rating the sibling's mental health on the FS³I, the mother rated her four at Time 2 which was an improvement over the rating of three she had assigned at Time 1.

Another mother was planning an Easter celebration similar to what they did at home:

...it's going to be nice because we're trying to keep it routine. Easter's not really a big thing for some people, but back at home we...do an Easter egg hunt; we dye the Easter eggs for my mom to put out. So I'm going to make it just [the same]. I went and bought the stuff. I got Easter basket stuff. I got eggs. Even though she's in here we're going to decorate. I'm going to go hide them, let the kids do their own little [Easter egg hunt]...

Care and caring. Both mothers who participated in the second phase of data collection referred to the number of nurses and doctors that they didn't know (*continuity and fit* subtheme). One mother, whose child had been on the medical/surgical unit for two and a half weeks at the time of the interview, identified this as a difference between the ICU and general care unit. However, the second mother, whose child had been transferred to the general care unit three days earlier, described her experience with multiple nurses and doctors in the ICU; the lack of nursing continuity affected her less on the general care unit since she was now staying overnight with her child but had not been in the past few weeks on the ICU.

It's not as bad here on the [medical/surgical] floor because I'm here all the time.

It's leaving, knowing you're leaving her with someone you don't know. So I'm not super picky here because I can be here to say "No, she doesn't like A, B, or C." I can be here to hold her hand through something. Nobody's going to walk away and go do something, because I'm here.

One mother was troubled by the increased number of nurses who didn't have "patience" and/or didn't "mold" with her child whom she later described as having become "very, very angry, and being very rude and nasty." This was in contrast to the other participant who again spoke of the *genuine caring for the child and family* that she experienced by her primary cardiologist and the nursing staff, both in the ICU and on the general care unit, at the time of both interviews. Other subthemes of *care and caring* are closely related to the new preliminary subtheme *considering the child's entire picture*.

Comparison to other themes from Time 1. The *child's critical illness and distress* was not specifically identified as a source of stress during the second phase of data collection. *Emotional stress* and *physical stress* were only discussed in relation to the services provided by the hospital to help families (e.g., massage, family fun nights); these were acknowledged as especially beneficial when a child had been hospitalized for a long time. New sources or alleviators of *job and financial stress* emerged: one family had recently obtained accommodations at the RMH which significantly decreased their lodging expenses, while another family had recently received an unexpected insurance bill because of the mother's leave of absence from work. The final theme, *what we've been through before*, specifically the subtheme *ongoing health care needs*, is related to the new preliminary subtheme *considering the child's entire picture*.

Themes. Two themes related to change in stress over time emerged from participants' responses during both Time 1 and Time 2 data collection: *stress builds* and *stress decreases as unknowns become known*. One additional subtheme of the *care and caring* theme, *considering the child's entire picture*, is presented but must be interpreted

with caution since it was identified from interviews with only two families who participated in Time 2 data collection. This subtheme will be discussed first, as it relates closely to the comparison of previous themes.

Preliminary subtheme (of care and caring theme): Considering the child's entire picture. Both participants who participated in data collection at Time 2 reported this as an important source of stress: the need to consider the child's present assessment and treatment within the larger context of the child's life and illness course.

There's a way to talk about things and a way to not talk about things. One doctor today was just like – we were just coming back from her swallow study so I'm like super excited that she passed, things are turning – and she's like, "Well you know, there's nothing more we can do for her medically, so she needs to have an ECHO tomorrow because there's nothing else left." And it's just like, "Whoa, whoa, whoa." I think people need to think about their wording and how far she's come, and not necessarily the fact that she's on a lot of meds. But also to me, she's still here... I think with doctors the big thing is they have to look at the child's entire picture, like [my daughter], it's her six months of life, not just the 60 seconds you checked in on her.

While this was primarily a concern with physicians, the concept of knowing the child's history was also tied to this mother's concerns about the number of new nurses she was still meeting at this point in her child's stay. It affected her stress about leaving the hospital and "trusting her care to someone else."

I really wish that there were less nurses, that they were more steady. I'd know that Monday through Friday I'd have Nurse A... Even with doctors they rotate. We've been here 50 some days now and I still see new people I've never seen before. ...

When am I going to see the same people who know [my daughter], who know her issues? ... When I'd call in and it would be someone I didn't know, my anxiety

would go through the roof and I'd think, "Should I come in?"

Although she shared that this source of stress about the nursing care hadn't changed since her first interview, "...continuously, if I didn't know who the nurse was taking care of her, it has been the biggest stress," she articulated different reasons that nursing *continuity* contributed to or alleviated her stress. Her focus at Time 1 was on nurses who demonstrated competence, *genuine caring* for her child as a person, and who were "always right there" in her room or directly outside her room and could quickly respond to acute changes in her condition (*availability*), while her focus at Time 2 was on nurses who knew her child and how she responded to interventions.

For another family, the primary stressor at this point in their daughter's hospitalization was related to the lack of respect that the physicians on the medical/surgical unit demonstrated for the surgeon whom they trusted and who knew their child best. This surgeon had been involved in her care since her initial clinic visit and had offered definitive treatment for a chronic illness for which she had been treated for six years, including 21 previous hospitalizations involving significant pain and limited hope for recovery.

... if [her surgeon] doesn't feel like it's a good thing to keep doing this and we need to go slow, then I feel like they need to go off what he says. That's what makes it stressful, because I feel like they're not listening to what he's saying and they're undermining his approach, which is not making that a very easy situation for me. So I really think that they need to take that into consideration, the whole stress thing. That is very hard, for a parent to listen to their surgeon of their child that has been inside twice now and seen. You can go off all the reports and you can go off whatever, but until you've physically seen it yourself, you can't go with what you think might be the best, always, for that child, either. And that makes it very stressful.

She perceived this difference in how the physician teams worked together as a difference in how patients were managed on the medical/surgical unit compared to the ICU, where she had commented numerous times in her first interview about how impressed she was that the teams were all *on the same page*. This mother reported more stress at the time of the second interview compared to the first and many of her comments were prefaced with statements such as this one made early in the second interview, “The stress level, I think, is higher up here [medical/surgical unit], honestly, than downstairs [ICU] right now, just because we've been here so long.”

Theme 9: Stress builds. This theme was apparent in interview responses and in comparing FILE scores pre-hospital to Time 1 and Time 2. In some cases, the buildup of stress resulted from the length of the hospitalization, but other sources of stress

manifested almost immediately upon admission for the child's critical illness or had been building prior to the hospitalization.

One mother described how stressors were "compounded" over the past six months as her young adult children were changing schools and jobs and she was expending significant effort to transition her 18-year-old developmentally-delayed daughter (the patient) to a new program and caregivers. Another mother listed a combination of past and present stressors, some specific to the illness that had led to her son's ICU admission (pre-hospital), the separation from her daughter at home and the stress of not sleeping well (current), as well as sources of stress associated with his chronic illness and the effects on their everyday routines (pre-hospital and current), commenting that "...it all just kind of builds, and builds, and builds." Another participant sympathized with a mother on the unit that she overheard saying:

"I just can't come back this weekend. I just have to take two days off." Her son's been here a super long time, but you kind of get it. If [my son] were here a long time, then I would have to take a weekend off, too because you just can't do it.

The stress associated with the length of the hospitalization was also seen in the patient and siblings. One mother described her hospitalized child as "angry again," and attributed it to the length of her hospitalization (more than five weeks) at Time 2. "I don't think she really even realizes how long she's been here."

Another mother told at Time 1 how her daughter at home was regressing in her development as the hospitalization became prolonged (LOS eight days at Time 1) and the mother had spent several nights at the hospital.

She's ready for her sister to be back and her mom to be back. It definitely makes it harder; I can see it's wearing on her, and she's getting more emotional. When I went home, she was crawling on the floor – she's three; she's been potty trained since she was two. When we were first in the NICU and stuff, she started to poop her pants, and now she's acting like a baby. [Crying] ... She knows how to write letters; she's not a baby.

FILE scores were another source of information regarding the change in sources of stress as participants reported a number of life events that had occurred in recent days, many as a direct result of the child's illness. Table J2 displays the change in FILE scores for each family comparing their baseline life events to those related to this episode of care. Although pre-hospital FILE results are not available for one family, when comparing responses on the FILE to findings from the interview with this mother, it appears that the large majority, if not all, of the life events she reported were present prior to this hospitalization, given the child's previous history of multiple hospitalizations as well as the nature of life events reported (e.g., death of the husband's father).

Because of the events related to the child's illness, four families' scores increased enough to place them in a higher category of stress compared to pre-hospitalization. Three of the four whose total scores were initially in the low category changed to moderate, and one went from moderate to high. The two families with the greatest change in total scores from pre-hospital to Time 1 had some of the lowest pre-hospital scores, both ranked low stress.

On average, “intrafamily strains” increased the most, followed by “illness and family ‘care’ strains.” For two families, the increase in “intrafamily strains” compounded what was already their greatest area of stress as measured by the FILE. This is consistent with the theme of *separation* since this subscore includes “increase of husband/father’s time away from family” and “increase of wife/mother’s time away from family”; another common item which contributed to this subscore was “increase in number of tasks/chores that don’t get done.” The two families who reported no change in intrafamily strains were on opposite ends of the continuum in Time 1 total scores; the family with the lowest total score reported no items in this category both pre-hospitalization and at Time 1, while the family with the highest total score also had the highest intrafamily subscore pre-hospital and at Time 1.

On average, the second largest increase was in the “illness and family ‘care’ strains” subscale. For most families this increase was directly related to this hospitalization (i.e., “child became seriously ill or injured,” “increased difficulty in managing a chronically ill or disabled member,” “experienced difficulty in arranging for satisfactory child care”). However, this was not new for one family who reported their child becoming seriously ill and increased difficulty in managing her chronic illness prior to this admission; the change for them was “increased responsibility to provide direct care or financial help to husband’s and/or wife’s parents.”

Although three families’ infants had planned admissions for repair of significant cardiac defects, there were some key differences. Unlike the family whose initial ranking was low (and remained low, even though their total score increased by 75%) the families

who experienced a greater degree of increase (greater than 200%) had at least one other child at home, identified separation from their children as a primary source of stress, and had had a family member move into their homes to take care of the sibling(s).

Factors which did not appear to contribute to the degree of change in stress included distance from the hospital, family stage, planned admission, or LOS. The family with the least change from pre-hospital to Time 1 had already undergone significant changes in the eight months prior to this hospitalization as a result of new onset of a chronic illness and increasing complications.

FILE data are available for only one family and are reported in Table 6 demonstrating continued pile-up of stress and change in sources of stress from the time of admission to Time 1 data collection, then between Time 1 and Time 2.

Table 6

Change in FILE Scores for Family 8

Pre-hospital	Time 1	Time 2	Change Pre-hospital to Time 1	Change Time 1 to Time 2	Subscores with change (# of points)
189 Low ^a	608 Moderate	754 Moderate	419 (222% increase)	146 (24% increase)	<ul style="list-style-type: none"> • Intrafamily strains (58) • Marital strains (58) • Illness & family “care” strains (18) • Finance & business strains (12)

Note. Participant selected different items at Time 2, including several more yes’s in intrafamily strains, although some items for which she selected yes at Time 1 were indicated as no at Time 2.

^aCategory per norm for family stage.

Theme 10: Stress decreases as the unknowns become known. This theme emerged from interview responses at both Time 1 and Time 2 during which families talked about the relationship between stress and unknowns in relation to change. One mother whose child had been in the ICU for ten days described a decrease in stress when

responding to the FS³I question regarding how much the family is bothered by this stressful situation:

In the grand scheme of things on our journey, you know maybe on day one, it would've been higher had I not known the progression of [my son's] healing here. So day one, it probably would've been high. But as we sit here today, it's probably a medium.

Another participant reported increased stress as her child's course became less clear in the eight days since she had been admitted.

I think it makes it more emotional, because I don't know where I'm going to be in a week, whereas I really thought [in] ten days, we'd be home and everything would be fine, and now I don't know. [Upset] And her diagnosis has changed too. They're worried about if she gets a common cold we'll be back in here and stuff like that, whereas I predicted seven days of hell and we'd be fine. It's the unknown prognosis and the unknown future that scares the crap out of me.

She added, "I really thought it was going to be scary then fine, and now I don't know where the fine is." This relationship between stress and unknowns was again demonstrated at Time 2 (hospital LOS 50 days) when this same mother (who not only reported less stress since the first interview but whose behavior was much more calm) reported that there was "still somewhat of an unknown, but I think she keeps proving herself day in and day out," then described her child's progress in weaning off her medications, having fewer symptoms, and being "back to herself." Her rating on the FS³I

question “How strongly do you feel this current situation/problem/concern will affect your family’s future?” was also lower at Time 2 (three compared to five at Time 1).

Summary of Findings

Although families reported a number of sources of stress directly related to their hospitalized child’s illness course and the care provided by the ICU team, the primary source of stress at Time 1 for every family with adolescent or younger children at home was separation and the constant pull that participants felt between the hospitalized child and the siblings at home. Emotional and physical stress for various family members contributed to their experience, as did baseline stress associated with life events common to family stage. Additionally, since the majority of children in this study had experienced ongoing health care needs, sources of stress related to past, present, and future health challenges emerged when complementary qualitative and quantitative methods were used to collect and analyze data for this study.

As the child’s condition progressed and the hospitalization became prolonged, the relative priority of various sources of stress changed. This included a shift from separation and unknowns as the most important sources of stress to aspects of the care and how it was provided becoming more essential to families’ experience of stress in pediatric critical care.

Chapter 5

Discussion of Findings

Introduction

In this chapter, the key study findings will be presented in relation to the conceptual model for the study, existing research studies, and the contribution to knowledge about sources of family stress in pediatric critical care and change over time. Strengths and limitations of the study will be reviewed and implications for nursing practice and future research will be presented.

Discussion of Key Findings

Aim 1: Sources of stress. The findings from this study provide insight into the sources of stress that families experience when a child is hospitalized in the PICU for more than seven days. Consistent with the study's conceptual model (Appendix B), stressors were identified that fit in both the PICU and home environments, and the concept of feeling torn between these two "worlds" emerged as a significant source of stress for mothers with children at home. The interaction of stressors within the various levels depicted in this ecological model was also supported; participants described stressors that affected the family, originating at the individual and family levels as well as within the parent-child and parent-parent dyads. The social-cultural and built environments were also found to influence family stress, some as sources of stress and others as alleviators.

Separation. The emergence of this important stressor – the constant pull between family members at the hospital and those at home – is a finding unique to this study.

Although previous research has recognized the importance families placed on maintaining integrity by fulfilling family roles and responsibilities not directly associated with the hospitalized child, most importantly performance of their parental role with siblings at home (Mu & Tomlinson, 1997; Turner et al., 1990), the significance of being apart and its effect on the family's stress has not been previously reported. In addition, separation of parents from each other was identified as a potential source of stress for some families as they coped with changes and uncertainty in the child's status. This could be anticipated since parents' support for each other has been identified as the most important source of coping (Mu & Tomlinson, 1997).

Although previous researchers acknowledged families' efforts to create normalcy for siblings (Mu & Tomlinson, 1997; Tomlinson et al., 1999), the present study offers additional understanding of the strategies they employed to address the issue of being apart. This included efforts to maintain routines by arranging for family members to assume caregiving responsibility, continuing school and daycare attendance and activities, and maintaining the expectation that siblings perform their usual responsibilities at home. Parents also expressed the importance of assuring siblings that they still had their parents' time and attention through daily phone or video calls, leaving encouraging notes for them to read each day, and ensuring smooth transitions when parents left home. Because a number of these admissions were planned, efforts to maintain normalcy for children at home began well before the child's admission to the hospital. While participants expressed gratitude for the support provided by extended family and friends to check in with them, provide meals, and be present at the hospital,

they appeared to need and appreciate most the support of grandparents, aunts, and uncles to care for the children at home.

Participants also appreciated hospital policies and design which supported siblings to be at the hospital, and preliminary findings suggest that this served to further alleviate the stress of separation as the hospital stay became more prolonged, allowing families to focus energy on addressing other concerns specific to the hospitalized child. This is different than previous literature in which the primary consideration was making sure siblings were well cared for at home and/or could be in a waiting room outside the ICU.

Fathers were likely to take on additional responsibilities with children at home (e.g., meal preparation, getting them ready for daycare or school, putting them to bed) while mothers stayed at the hospital. Families also discussed factors influencing parents' decisions to leave the hospital to maintain other family responsibilities; these were similar to those reported in previous research such as ready availability of nurses to provide updates by phone, as well as information about what to anticipate and the best time to be away from their child.

Discussion of separation. The identification of separation as an important stressor in this study, unlike studies conducted in past decades, may be related to the paradigm shift which has occurred from thinking of families as “visitors” and has resulted in families being present in the child’s room and integrated in the child’s care. This shift is reflected in hospital and ICU design which supports family members to be in the child’s hospital room, one parent to sleep in the room, and siblings to be welcome on the unit

and in patient rooms. The ICU in which this study was conducted consists of individual patient rooms, each with its own family area with seating, desk, and a computer; a curtain which can be pulled between the patient and the family areas; and a pullout couch where one parent can sleep. (This is significantly different than the typical PICU as recent as five years ago, and although a number of PICUs in the United States have newly designed PICUs which incorporate these design features, they have not been universally implemented. Giannini & Miccinesi, 2011; Meert, Clark & Eggly, 2013; Smith, Hefley & Anand, 2007). One mother in this study summarized improvements that had been made over the years to provide accommodations to incorporate families in their child's care, commenting on her previous experience with multiple patient rooms in units with "no sleeping in the patient's room and only one person gets a chair," as well as the way the hospital had "evolved to having a warmth and a patient-nurturing feel."

The study design may also contribute to this finding of being apart as a primary source of stress. Since data were collected later in the stay than in previous research, families had time to take in and deal with the immediate stressors of the child's illness as well as the ICU environment and personnel prior to participation, and thus may have been able to attend to the broader context of their families' stress. The qualitative methodology also allowed families to define what was a stressor, unlike previous quantitative studies for which the focus had been specified based on the most important stressors identified in older qualitative results (e.g., the nurse/family interface, PSS:PICU dimensions, uncertainty). It is also likely that the focus of the interview (i.e., "stress on

your family”) and the tools turned their focus to the family unit, not only the individual parent or parent-hospitalized child relationship.

It is also important to note that this finding of separation as a primary stressor reflects the perspective of mothers who were staying at the hospital all or most of the time, and only those with other children at home. The experience of feeling torn may not be the same for fathers, siblings, or patients, or for mothers who do not spend the majority of their time at the hospital. Some mothers expressed confidence that living patterns hadn't changed significantly for their other children and/or husbands at home who were “doing the same thing” (going to work, school, daycare) and that the parents felt the effect of the separation “more right now than the kids do.” However, Shudy et al.'s (2006) review of the limited literature on stress on siblings concluded that their main sources of stress were care by a substitute caregiver and changes in parental behavior. Therefore, further exploration is needed to validate this perception with data from fathers and siblings as it may have more of an effect than some mothers realized.

Not knowing. Uncertainty within the context of a child's critical illness is well described in the literature on family stress. In fact, the foundation for the majority of family stress studies reviewed in Chapter 3 was a study in which Turner et al. (1990) identified four realms of uncertainty for PICU parents: environmental, illness, family system, and caregiver uncertainty.

Illness uncertainty. Of the dimensions of uncertainty identified by Turner et al. (1990), the most similar source of stress compared to the present study was in the area of illness uncertainty, specifically their subtheme “expected course and prognosis” (p. 56).

The theme of unknowns about the child's course emerged from every participant in the present study and for two families this was a primary source of stress. This is similar to Mu and Tomlinson's (1997) finding that uncertainty about the child's prognosis and whether it was under health professionals' control was an important factor in how parents experienced the child's condition.

A subtheme that emerged in the present study relates to families' belief that although they thought they were prepared for changes in the child's course, when changes actually happened, the preparation didn't always moderate their response. This inability to prepare psychologically was not because of a lack of information or effort on the part of the health care team to prepare them for what may happen. This perception did not emerge in reports from other studies. Previous literature which addressed families' perceptions about being prepared often considered planned vs. unplanned admission as an important determinant of preparation, and "clear communication" has been cited as a prominent feature in interventions that have demonstrated decreased parent stress (Shudy et al., 2006). Thus the perception of not feeling prepared for the unknowns of their child's course, regardless of information shared by the team and parents' efforts to prepare themselves, is an important finding, as it could be inferred from some previous investigations that if health care providers communicated more frequently and effectively, it may mitigate the stress of not knowing.

While at least one study demonstrated that preparing parents for some aspects of the PICU experience decreased stress scores in the areas of procedures done to the child, staff behaviors, and child's appearance (Miles & Mathes, 1991), Mu and Tomlinson

(1997) found that evidence of the child's recovery was the only thing that served to "completely ease parental worry about actual loss or loss of the healthy child," which was not accomplished by information alone (p. 620). This supports the present study's finding that information may relieve stress about some aspects of the PICU experience, but not about the uncertainty of the child's course.

"Eventual quality of the child's life," another subtheme of illness uncertainty (Turner et al, 1990, p. 56), was identified as a concern by only one participant in the present study while others indicated that they weren't thinking that far ahead. Instead, a key strategy in response to the "roller coaster" of their child's course was to not plan beyond today, as they had come to view their child's progression as a series of "baby steps," often punctuated by periods of waiting and/or setbacks.

Family system and caregiver uncertainty. Although unknowns were an important source of stress for families in the present study, unlike Turner et al.'s (1990) study the relative importance of sources of stress and uncertainty were different than those identified in the present study. These authors prioritized the need to "focus on family role uncertainty, care uncertainty relative to the surrogate parent role of the nurse, and institutional factors that affect family role performances" (Turner et al., 1990, p. 60), thus leading to development of an empiric measure of family-nurse boundary ambiguity with the ultimate goal of "assisting the family in its task of family caregiving within the healthcare system" (Tomlinson & Harbaugh, 2004, p. 400). This was followed by identification of nursing interventions to decrease stress at the nurse-family boundary (Tomlinson et al., 1999), and testing of an intervention to role model nursing behaviors to

increase sensitivity to family care/needs (Peden-McAlpine et al., 2005; Tomlinson et al., 2012).

The importance of understanding and intervening at the family-nurse interface was supported by numerous studies that found that the most stressful aspect of PICU hospitalization for parents was strain on their parental role (Board & Ryan-Wenger, 2000; Shudy et al., 2006), which resulted from the sudden need to depend on the health care team for their child's care (Board & Ryan-Wenger, 2000; Mu & Tomlinson, 1997). However, the only representation of boundary expansion that emerged in the present study related to allowing others to care for siblings at home to help maintain family functioning outside the hospital. Parents in the present study described adjusting to "a different type of parenting," but there did not appear to be the same conscious consideration of family-nurse interaction as described by families in Mu and Tomlinson's (1997) study when they referred to expanding the boundary to incorporate nurses.

Environmental uncertainty. Another factor which did *not* emerge in this study as an area of uncertainty in the same way previously reported is that of the PICU environment. Unlike studies using the PSS:PICU which identified "sights and sounds of the unit" among the most stressful for parents (Board & Ryan-Wenger, 2002, p. 59), families in this study denied that the environment was a source of stress; in fact, participants who spoke about the environment described many aspects that helped alleviate their stress. Specifically, the individual patient room and the family space in the child's room were acknowledged as helpful; the family space was a place "just to be," to have a private area to go "on the hard days," and to have a computer where parents could

watch something other than a “kid movie.” Even though they could hear the alarms, which sometimes added to their stress, it was apparent that proximity to their hospitalized children was essential. Having places for siblings to spend time on the unit and elsewhere in the hospital was also appreciated.

Discussion of uncertainty. A number of factors contribute to differences in the types and relative priority of stressors related to uncertainty in this study compared to previous literature, primarily timing of data collection and changes in care delivery models. Since data were collected seven to 17 days after admission, it is likely that families had become familiar with the social-cultural and built environment of the ICU in the days prior to data collection. This interpretation is supported by Turner et al.’s (1990) finding that boundary uncertainty decreased as parents’ and staff’s perceptions of their individual and shared roles became more congruent, as well as evidence that “sensitivity to environmental stimuli in the PICU becomes less acute over time” while staff communication and behavior became “stronger determinants of parental stress” (Shudy et al., 2006, pp. S205, 7).

Another potential explanation for this disparity is the significant change that has occurred in standard of care in this unit as it relates to incorporation of families into the minute-by-minute care of the child and the accompanying anticipatory and real-time preparation that nurses, child life specialists, social workers, and other team members provide. The expectation that families will be present in the ICU and involved in their child’s care regardless of acuity and level of awareness provides a greater level of support and intentional role modeling of parent involvement in the care, as well as coaching in

how to interpret alarms and other stimuli of the ICU. Their constant presence at the bedside also provides a greater degree of exposure to the sights and sounds of the unit and experience parenting in this environment, although it is an ongoing effort, described by one father as “part of the roller coaster, that you just have to not be concerned with the beeps.” This interpretation is supported by Smith et al.’s (2007) finding that PSS:PICU scores were significantly lower for parents of children hospitalized in two PICUs with parent bed spaces ($n = 92$) compared to parents whose children had been admitted to those hospitals prior to construction of new units with parent bed spaces in the patient rooms ($n = 86$). Similarly, scores on the parent role alteration and child’s appearance scores were significantly lower after the redesign. This resulted in a change in which dimensions were most stressful: in the old units, parent role alteration was the highest subscore, followed by child’s appearance, and procedures; in the new units, procedures ranked highest on average, with parent role alteration, and child’s appearance ranked second and third.

Child’s illness and distress. Participants in the present study identified the child’s critical illness and distress as important sources of stress. This stressor is reflected in the PSS:PICU in that a number of dimensions of this instrument include specific items related to this theme (e.g., child behavior and emotions, procedures, child’s appearance) which have been reported as among the most stressful for parents, in addition to parent role alteration (Board & Ryan-Wenger, 2000; Board & Ryan-Wenger, 2002; Saied, 2006). Families also experienced more family-nurse boundary ambiguity when they perceived their child’s awareness to be low (Tomlinson & Harbaugh, 2004). Level of

awareness was a factor in the present study although not in the same way as in previous studies; some parents of infants who were sedated expressed ambivalence about whether to leave the hospital or to stay since “there’s nothing we can do.” For another participant, her child’s sedation (i.e., low level of awareness) helped relieve her family’s greatest source of stress (the distress she manifested when she was awake and agitated).

Although participants in other studies expressed concern about the loss of their child as a result of this critical illness, that theme did not emerge from interviews with most participants in this study. Instead, expressions of hope for their child’s recovery were common even though these children were acutely ill at the time of the interviews and had significant health challenges in their past and future. Hope was expressed as “the light at the end of the tunnel,” confidence that the child would outgrow some conditions (e.g., febrile seizures), and “this is going to be a heck of a six months and then she’s going to be great.” Families expressed the need to balance optimism and reality; one mother alluded to the potential loss of her child, but the overall tone of her interview reflected her optimism that the outcome would be positive.

Care and caring of the ICU team. Participants in the present study expressed confidence in the care and the caring of the ICU team and the role that various behaviors and attitudes played in relieving their stress, although there were a few examples of things that contributed to their stress. Themes were similar to those from previous research and can be broadly categorized as communication (between team members, between families and team members) and caring (for the child, for the family).

In regard to communication, reports of “being given all the information we can be given,” listening to parents as experts on their children, and advocacy were consistent with the literature which identified quality of communication (Mu & Tomlinson, 1997); addressing families’ need to know; respecting family rights by informing/orienting them and including them in care and decisions; and strengthening the family boundary by being honest and trustworthy, helping them to anticipate next steps so they could plan, and supporting them to know when to stay or go (Tomlinson et al., 1999). Staff communication has been shown to make a significant contribution to parent stress (Saied, 2006). One finding that emerged in this study but is not reported in previous literature is the importance of team members being “on the same page”; this was cited in relation to ICU resident and attending physicians rotating, multiple subspecialists involved in the care, and nurses communicating individualized strategies that were effective for and/or preferred by the particular child and family.

Families’ acknowledgement of the need for and experience with advocacy for their children is another area addressed by this study. Every participant who had previous experience with hospitalization spoke of the need for advocacy and shared what they had learned about their role as advocates and what they needed to do to be heard, which often involved expressing concerns and needs to the charge nurse.

The child’s care and how it was provided was also a source of stress or helped prevent stress. Continuity of nursing care and behaviors that demonstrated genuine caring for both the child and family were important aspects of this theme. This is consistent with previous studies that identified attitude; efficiency; professionalism; motives (Mu &

Tomlinson, 1997); fostering normalcy through recognizing the child within; and promoting families' comforting and connecting with their child (Tomlinson et al., 1999) as behaviors and attitudes that influenced family stress. While the majority of participants described their experience receiving communication and care that was consistent with the best practices identified in previous literature, it was evident that a single caregiver who does not follow these recommendations makes a significant (negative) impression which may overshadow the positive interactions that families have with other team members.

Another theme related to the care – availability of the team – has not been recognized in previous reports of family stress in PICU. This may be a result of parents being present in the child's room and thus aware of who is typically around at different times of the day and night, unlike times in recent PICU history when families did not routinely stay in the patient's room. Both this and the theme of "being on the same page" may be somewhat unique to an academic center such as the one in which this study was conducted, because of the teaching environment with rotation of resident physicians and the complexity of the patients who seek care in this setting and require consultation from several subspecialists.

While the majority of participants in the present study identified aspects of communication as potential sources of stress but had not personally experienced them, communication with team members was a source of stress for participants in previous studies. Reasons for this difference in finding are likely due to changes in this ICU's care delivery model which now includes routine involvement of parents in nursing handoffs and daily interdisciplinary rounds, which has been found to increase parents' confidence

in the medical team (Aronson, Yau, Helfaier & Morrison, 2009). Additionally, since families have a place to stay in the patient room, they are more likely to be available when various team members enter the patient's room to assess and care for the patient, and are thus "in the right place at the right time" to receive communication and participate in planning care.

Emotional stress. Manifestations of emotional stress identified in previous research include anxiety, confusion, anger, and depression (Board & Ryan-Wenger, 2000). Although the present study did not measure these types of effects, families discussed sources of stress similar to those identified in the PSS:PICU (e.g., procedures, appearance of child) and described their overall experience of being more emotional in response to this event.

Mothers' perceptions of differences in their husbands' sources and responses to stress (i.e., anger, exhaustion) were also expressed. Since these perceptions were not validated with fathers, this cannot be assumed to accurately represent their perspectives, although previous parental stress studies have confirmed that the most stressful dimensions on the PSS:PICU were sometimes different for fathers (Board & Ryan-Wenger, 2000; Saied, 2006).

A source of stress identified in this study but not reported from previous research is the stress of talking about their child's illness to family and friends. Because families were interviewed well after the initial crisis of the illness and hospitalization, they had already shared basic information about their child's illness and further discussion at this point was described as "this perpetual conversation" in which there was nothing new to

share. For some families who identified this as a stressor, this hospitalization was one of many and they did not want to open themselves up to their relatives' negative responses and concerns which added to their stress. Saied (2006) examined relationships between family stress and social support, identifying an inverse relationship between stress (PSS:PICU and FILE) and use of social support; however, since the families whose responses contributed to this theme were not those with the highest FILE scores in the present sample, Saied's (2006) finding is not corroborated by this study. However, this finding does complement those from previous studies which suggested that families focus on social support that helps them directly with the situation of having a child in the ICU (e.g., nurses, family members to care for siblings) (Mu & Tomlinson, 1997).

Physical stress Lack of sleep has been identified in previous literature as a source of physical stress (Shudy et al., 2006) and was a factor in Turner et al.'s (1990) dimension of "inter-role uncertainty" (a subtheme of "family system uncertainty") as families determined how to prioritize demands related to the hospitalized child with those of meeting their own needs for food and sleep. Participants in this sample reported this in addition to stressors related to inactivity and unhealthy eating.

This study also offers additional insight into ways in which couples support each other to take care of their physical needs. Mothers discussed their husbands' support and reminders to take care of themselves, as mothers were unlikely to prioritize self care in their efforts to focus on their children (both hospitalized and at home). The importance of addressing physical stress in order to maintain their own physical health and enhance coping was emphasized.

Job and financial stress. While the need to maintain job responsibilities and fulfill financial obligations have been recognized as important for maintenance of family integrity (Tomlinson et al., 1999), the present study highlights the importance of job flexibility and benefits in mitigating stress and allowing families to attend to their ill child and other children at home. Even though families didn't always speak of financial strains in the interviews, their responses on the finance and business strains subscale of the FILE revealed that a number of them had experienced financial strains prior to and/or as a direct result of this hospitalization. Regardless of their scores on this subscale, it was common for families to comment on feeling blessed and acknowledging that others needed resources such as the RMH more than they did, and a number of families expressed the intention to "give back." Although other investigators used the FILE to quantify stress soon after admission, subscale information was not reported (Board & Ryan-Wenger, 2002) or a revised version of the FILE was used (Saied, 2006) so it is not possible to compare their findings about the contribution of financial strains to the pile-up of stress in the present study

Baseline stress and ongoing health care needs. The number and types of baseline stressors varied across families, similar to the large variation that Board and Ryan-Wenger (2002) found in FILE scores within 24 hours of PICU admission (*SD* 323). Even though a number of families had been dealing with ongoing health needs prior to this hospitalization, FILE scores were in the low or moderate category at the time of admission to the ICU. For some, effects of the child's ongoing health care needs made a significant contribution to their total FILE scores; for others, baseline stress was more

related to changes typical for their family's stage (e.g., launching young adults).

Regardless of type of stresses and strains, the degree of baseline stress contributed to their present response, and their success dealing with previous similar situations was related to their level of confidence that they could effectively deal with this stressor.

An important contribution of this study is in beginning to describe the experience of PICU families for whom this admission was one event in a series of ongoing health challenges (six families) or who were beginning the journey with a child who would continue with special health care needs (two families). In addition to the analysis of qualitative data and the essence of what each family shared in light of Rolland's (1997) description of chronic illness phases (Table 5), quantitative (FILE) data were used to explore the contribution of ongoing health care needs within each subcategory of life events measured by the FILE. This analysis was enhanced by explanations that participants offered while completing the instrument as well as analysis at the individual family level. One key example of the added stresses and strains resulting from ongoing health care needs was the change that a number of mothers had made (or were making) in their jobs and careers because of their children's special health care needs.

The role of ongoing health care needs could not be explored in this way in previous studies since some excluded families whose children had physical or developmental disabilities or had been diagnosed with a chronic illness (Board & Ryan-Wenger, 2002) and others included them but did not analyze their data separately (Saied, 2006). Therefore, it is unknown whether FILE scores and types of stressors were different than for families whose children had no previous health care needs. Similarly,

the role of prior hospitalizations in families' response to the current crisis is not apparent from previous literature although, similar to the present study, a number of investigators reported that 45 to 50% of families had experienced previous ICU admissions (Tomlinson et al., 1999; Turner et al, 1990). Since results for those with previous hospitalizations were not consistently differentiated from those of families who didn't have prior admissions, conclusions cannot be drawn about how previous experience affected their response to the current hospitalization, other than Tomlinson and Harbaugh's (2004) report that previous admission did not influence the level of ambiguity reported at the family-nurse boundary (their definition of family stress).

Aim 2: Change in sources of stress. Both qualitative and quantitative data demonstrated an increase in sources of stress over the course of the hospital stay, but the relative importance of each type of stressor changed as the child's course became more certain and as the course was prolonged.

Stress builds. The concept of compounding stressors emerged both from interviews and FILE scores. A number of FILE subscales indicated an increase in stressors between the pre-hospitalization period and the first phase of data collection (i.e., within the first one to two weeks of ICU admission). These increases were most commonly in the areas of intrafamily strains (reflecting the effects of separation) and illness and family care strains, and were almost always directly related to the child's hospitalization and acute illness. Time 2 FILE data are available for only one family; they indicate an additional increase in total score, although considerably smaller than the change between pre-hospitalization and Time 1.

Only one other study examined the change in family stress over time, comparing FILE scores within 24 hours of PICU admission and five to six months later, indicating increase in life events over time (Board & Ryan-Wenger, 2002). These investigators excluded families with a diagnosis of chronic illness, but still found that a number of participants experienced an increase in parent stress symptoms over time; those who reported more stress symptoms had experienced more life events in the past year, had children who were more seriously ill during the hospitalization, and perceived their families as more dysfunctional (Board & Ryan-Wenger, 2002). In the present study families reported that they were functioning well (in FS³I responses), although this was not measured using a family functioning scale as in previous studies. Many talked about “pulling together,” becoming closer as the result of their child’s health challenges, and functioning at a higher level as a family. However, the one participant who completed the FS³I at Time 2 rated her family’s ability to help themselves lower at Time 2 than Time 1 (three compared to five), perhaps as a result of the pile-up of stressors over time. In several cases participants attributed their functioning to the quality and quantity of their communication which is consistent with investigations that have found a positive relationship between communication and family functioning (Saied, 2006).

Shift in priority of stress sources. When findings from Time 2 were compared to themes from Time 1, a number of the same themes were present, but their magnitude and order of importance had changed. Stress within the family system was still present but decreased in key areas (e.g., *separation*), and hospitalized child-specific stressors shifted

from *unknowns* about the child's course and prognosis to concerns related to *care and caring* (e.g., *continuity* of caregivers, recognition of the child's big picture).

The absence or significant decrease in *unknowns*, which is closely related to the child's illness acuity, may explain in large part families' shift to focus on other stressors as well as their ability to spend time together and thus alleviate the stress of separation. This was illustrated by one family for whom the decreased effect of separation on the sibling (and thus her mother) was apparent at Time 2; because the child's condition had improved, the mother was able to sleep at home during the previous two weeks of the ICU stay and the sibling had come to the hospital several times (unlike earlier in the stay when she was too traumatized by seeing her sister critically ill). This provides support for the theme relating stress and unknowns.

Stress decreases as the unknowns become known. Participants shared how stress decreased as the child's course and outcome became more certain, similar to Mu and Tomlinson's (1997) report that parents experienced uncertainty about the child's condition early in the hospitalization. One mother described an increase in her family's stress at the first phase of data collection when she had come to realize that her child's course and outcome were not as clear as she had originally anticipated at the time of admission for surgical repair of a cardiac defect. However, by the second phase of data collection, unknowns were not as stressful to her, as her child's condition had improved. This is consistent with the theme of the *roller coaster* identified in this study and in Carnevale's (1999) investigation conducted with ten PICU families who described prolonged periods of uncertainty, involving a "series of declines and improvements in

condition, with associated parental discouragement and excitement” (p. 18). Similarly Rolland (1997) described how strain on the family experiencing chronic illness is “caused by both the frequency of transitions between crisis and noncrisis and the ongoing uncertainty of *when* a recurrence will occur” (p. 2). It is likely that this decrease in stress related to unknowns was seen because their children’s condition was improving; a similar decrease and shift to focus on other stressors may not be seen in families whose children are still critically ill and unstable several weeks into their hospital stay.

Change in sources of stress over time. As the hospital stay became prolonged and improvement in the child’s condition (regardless how gradual) allowed families to focus on other factors affecting their stress, the focus and priority moved to aspects of *care and caring* while several sources of stress identified at Time 1 were not even discussed, or had become stress alleviators. It is possible that these stressors related to *care and caring* contributed more to families’ stress during the second data collection phase because they perceived relatively less stress in general, and their stress specific to the child’s illness was considerably less compared to Time 1 (despite an increase in the “raw number” of stressors such as those described by the FILE). Since both mothers who participated at Time 2 had been transferred out of the ICU, it is also possible that some changes in sources of stress reflect differences in care delivery models on the general care unit compared to the ICU. One key stressor that emerged from analysis of Time 2 data was related to caregivers not seeing a bigger picture, which fits within the original theme of *care and caring*.

Considering the child's entire picture. Participants experienced stress when physicians did not consider how their present actions and the child's current condition fit in the overall context of clinical progress and past and future treatment. Rotation of physician providers and lack of continuity with nurse assignments contributed to the frustration that physicians weren't "putting it in the big picture of all that she's gone through" and families' anxiety about "trusting their child's care to a stranger."

This reflects a change from the findings from Time 1 data collection when the majority of participants perceived that team members were on the same page, although nursing continuity was a concern for some participants at that time. Because these families had been in the hospital for five to six weeks at Time 2, they expected a certain degree of continuity of nursing assignments although this was not always the reality. When the child was assigned to a nurse who did not know her, stress was increased because of concern for how the nurse would relate to the child and interpret assessment findings without knowing the context of the child's illness and her typical responses to interventions. This is consistent with the finding from the pilot study conducted with mothers whose children had been in the hospital for three to seven weeks and the nurses who were their consistent caregivers; an important factor in families' experience of stress was the presence of nurses who consistently cared for and knew the individual child. Even though other nurses were perceived as competent, they didn't have the same depth of knowledge of the child's unique needs and responses (e.g., signs and symptoms, likes and dislikes, tolerance of interventions), and parents were more likely to leave the hospital to spend time with their families when the child's consistent nurses were present

(Hagstrom, 2013). This may be more related to the complexity of this population of children who require long and/or frequent hospital stays and less specific to the long hospital stay itself.

Population and methodological differences. In addition to the new insights identified in this study regarding the sources of stress for families in pediatric critical care, the findings also provide unique information for a number of reasons. In this study, data were collected later in the hospital stay, the entire sample consisted of families whose children had ongoing health care needs, and complementary qualitative and quantitative methods were used for data collection and analysis.

Timing. Data were collected for this study after families had been in the ICU from seven to 17 days and four to five weeks thereafter; therefore findings reflect a different understanding of their child's illness and their family's response compared to studies conducted with 24 to 48 hours of admission (Board & Ryan-Wenger, 2002; Turner et al., 1990) or return from the operating room (Saied, 2006). One previous study included some families whose children had been in the ICU for 12-15 days, but findings were combined with those interviewed within two to seven days after admission (Mu & Tomlinson, 1997), so it is unknown if their experience of stress was different.

Demographics. The present study is similar to other family stress studies in terms of demographics. Overall, the sample in each study was heterogeneous in terms of child's age, reason for admission, and planned vs. unplanned admission. Although a number of studies did not exclude older children, most were six years or younger (Board & Ryan-Wenger, 2002; Mu & Tomlinson, 1997; Saied, 2006; Tomlinson et al., 1999; Turner et

al., 1990); children whose families participated in the present study ranged in age from nine days to 18 years. Reasons for admission in this study and most others included both medical and surgical diagnoses (Board & Ryan-Wenger, 2002; Tomlinson et al., 1999; Turner et al., 1990), except one study that included only children undergoing cardiac surgery (Saied, 2006). Percentage of unplanned admissions ranged from 13 to 74 in studies for which this was reported (Board & Ryan-Wenger, 2002; Tomlinson & Harbaugh, 1990; Turner et al., 1990); 50% of admissions in this study were unplanned.

Respondents. The present study included the mother from each family and one father. In some studies, the majority of participants were mothers (Board & Ryan-Wenger, 2002; Saied, 2006) while both parents have participated in other studies (Mu & Tomlinson, 1997; Turner et al., 1990; Tomlinson et al., 1999).

Summary of Contribution of this Study

Key findings of this study which are not represented in other published studies of family stress in pediatric critical care include the stress associated with separation of family members at home from those in the hospital, the perception of “not being prepared” despite efforts to prepare, stress caused by team members not being on the same page, availability of the team, not wanting to talk about it, and the role of baseline stress including that associated with the child’s ongoing health care needs. It also offers preliminary information about the experience of families whose children have been in the hospital for more than four weeks and how their sources of stress change over time. Other insights that it adds to existing evidence include more information about mothers’

perceptions of fathers' sources and responses to this stress and the support that fathers provide to mothers in the area of mitigating physical stress.

Another important finding is the absence of stressors identified as key in previous literature, namely parent role alteration and/or nurse-family boundary ambiguity and the PICU environment as a source of stress and/or uncertainty. These differences may be due to a number of factors including data collection later in the hospital course (after families have become accustomed to PICU practices and environment), as well as evolution in how care is provided in many PICUs today. The environment, care delivery models, and philosophy of care in the ICU in which this study was conducted are significantly different compared to study sites from previous decades.

Because the majority of families in the present study had previous hospitalizations and all had ongoing health care needs, findings from this investigation add the perspective of chronic illness and the population typical in a tertiary care center. The use of mixed methods offers a new perspective on the interplay of various child and family characteristics with sources of stress at various levels (individual, family) and in different times (pre-hospital life events, immediately after admission, days or weeks after admission) that has not been described previously and warrants further exploration.

Critique of the Study

Strengths. An important strength of this study is the use of both qualitative and quantitative data collection methods and analysis to enhance understanding of families' experience of stress in pediatric critical care. Each provided information about different sources of stress and change over time, and participants' verbal explanations of their

responses to items on the quantitative instruments enhanced understanding of their experience, leading to richer insight into each individual family's experience.

The order of data collection, beginning with a semi-structured interview, allowed participants to describe their experience in their own words and provided narrative about stressors specific to the child's illness and ICU care, as well as stress on the family system. This was followed by completion of the FILE and FS³I which stimulated additional insight into the stressful life events (FILE) as well as family strengths and stressors they experienced as a result of the event of PICU hospitalization (FS³I). This order and combination of data collection methods resulted in themes related to stressors at every level (individual, family, dyad), all of which influence the family stress experience.

Another strength of this study is the PI's status as an "insider." The PI's professional experience and role on the unit created an environment of trust and credibility for participants about the phenomenon under study. Families expressed their belief that by sharing their experiences they were helping other families. Bedside nurses were the first to approach potential participants about the study, and their relationship with the families was a factor in their willingness to consider participation. From a practical standpoint, the PI's availability on site and flexibility to accommodate participants' often unpredictable activities and need to be with their children permitted recruitment and data collection with families that would otherwise not have been able to participate; this was particularly important for the second phase of data collection when the children had been transferred out of the ICU.

Limitations. Study limitations include small sample size, lack of diversity in terms of ethnicity, culture, and family structure. Although both fathers and mothers were invited to participate, only one father was available and willing to participate; therefore, data reflect mothers' perspectives almost exclusively.

Another significant limitation was the difficulty recruiting families whose children stayed in the ICU long enough to participate in the second phase of data collection. This was, in large part, due to an unexpected decrease in patient volumes after resignation of a cardiac surgeon followed by the organization's efforts to evaluate the best model for care delivery within the local children's hospital market. Given increasing evidence of an inverse relationship between hospital volume and surgical mortality, payers have advocated for volume-based referral (Finks, Osborne & Birkmeyer, 2011). While the contribution of patient volume to surgical mortality is less clear in pediatric cardiac surgery (Vinocur, Menk, Connett, Moller & Kochilas, 2013), the hospital in which this study was conducted was undergoing an evaluation of potential partnerships, which led to patients being referred to other centers during this study's recruitment period.

In an effort to broaden the study criteria without compromising the intent, the study protocol was revised to include families who had transferred to a general care unit but were still in the hospital four weeks after Time 1 data collection. However, only two families met the expanded criteria, thus limiting the ability to draw conclusions in the depth desired for Aim 2. Since both of these families had been transferred out of the ICU because their children were improving, mothers' ability to spend time away from their

children was limited. As a result, the interview with one family was interrupted, and despite multiple attempts to complete the interview and instruments, she was unable to finish participation. The interview with the second mother was ultimately moved to the patient's room so she could care for her daughter during the interview; the instruments were left with her to complete when the child was asleep. This did not allow for discussion and explanation of responses as she and many others had provided during Time 1 data collection.

Another potential limitation is the validity of the FILE in this setting and/or during a crisis. Some participants did not indicate "yes" for items that the researcher knew had occurred in the past 12 months (e.g., "birth of a child" in a family whose infant was in the ICU). The participant who completed the FILE at both Time 1 and Time 2 selected different items each time she completed the instrument; although it was expected that she may select "yes" for new items at Time 2, for some items which she had selected "yes" at Time 1 (indicating the event had happened in her family in the past 12 months), she selected "no" at Time 2. Although this instrument or a modified version has been used in previous studies in PICU (Board & Ryan-Wenger, 2002; Saied, 2006), and test-retest reliability has been established (McCubbin et al., 1996), this participant's responses and analysis of change over time must be interpreted with caution.

Implications for Practice

The findings from this study offer a number of insights and recommendations to incorporate into nursing practice, specifically in relation to care for the family and the way in which patient care and communication are provided. First, nurses need to

recognize the significant role that separation from other children plays in mothers' stress, and the constant "pull" they feel between the hospitalized child and siblings at home. Until interventions can be identified that may help alleviate this stress, nurses should begin by asking families about it as a potential source of stress, acknowledging its importance, and providing guidance about the best times for them to be away from the bedside to attend to children at home. Another important source of stress is associated with the "ups and downs" both of the child's illness as well as parents' feelings about how things are going. Nurses can support families by assessing how each family is feeling and acknowledging the difficulty of "the roller coaster," recognizing that the family's highs and lows may not be at obvious times (i.e., related to the patient's ups and downs).

PICU nurses can also reduce families' stress by making an effort to understand the context of the family and the overall course of the child's health status. As the professional who spends the most time with the patient, the nurse is uniquely positioned to communicate this context to physicians and other team members who may tend to look at this episode of care (or even this moment in time) in isolation. This is particularly important in ICUs such as the one in which this study was conducted, since the number of patients with long and complex medical histories is growing and physician rotation is a reality of the academic health care environment.

Similarly, nurses play a critical role in helping families interpret messages from different team members and subspecialists, ensuring that families have opportunities to ask questions to help them understand how it all fits together. Nursing staffing models

should provide for continuity of assignments as this helps decrease families' stress in a number of ways. Nurses can help ensure that proposed changes to the plan of care are appropriate given the patient's overall health status and previous response to interventions; this helps eliminate the need for parents to continually retell their story. Parents are also more likely to be able to sleep or leave the hospital when children are in the care of nurses who know the child and are perceived as trustworthy to provide excellent care in a way that demonstrates that they genuinely care about the child as a person and that this isn't "just a job."

The importance of caring, not just technical competence, is an important factor in families' perceptions of stress in the PICU. Nursing leaders need to hire and socialize nurses to be competent in providing holistic nursing care. Just as families evaluate nurses and their caring based on what they say and how they say it, leaders should measure their staff's performance not only by the ability to effectively care for the physical needs of the patient, but also by their behaviors, skills, and effectiveness interacting with families.

Interviews and instrument completion for this study brought to light numerous sources of stress that are not routinely shared with nurses. Families demonstrated openness to share their perceptions and experiences with the researcher when asked. Because nurses develop trusting relationships with their patients' families, it is likely that families will also share openly with nurses who take the time to sensitively solicit this type of information. While many of these sources of stress cannot be addressed by nurses, asking about what is causing stress for a family gives the nurse the opportunity to help triage to social workers, child life specialists, and others the stressors for which there are

“solutions” and provide supportive listening for others. This awareness also provides insight for the nurse about the backdrop of stress upon which the crisis of PICU hospitalization is set for the individual family; this is critical information for the nurse since the baseline pile-up of stressors, added to those of the child’s illness and effects on the family, influence families’ responses to acute events in the hospital.

Implications for Future Research

This study offers a beginning exploration of the stress families experience when their child is hospitalized in the PICU for two weeks and longer, and raises a number of questions for which further research is needed to understand sources of stress, relationships between specific aspects of the care, and how they influence stress over time. Exploration is also important to differentiate the influence that transfer to the general care unit has compared to results of being in the hospital for so long.

The role of separation as a significant source of stress needs to be validated in other samples, types of settings, and with other family members. Interventions to address this stressor also require exploration. It would also be interesting to compare the stress of mothers whose husbands are supportive to those who are not, as preliminary impressions from this study suggest that there may be patterns in how they perceive the stress of this experience. Research with single parents, grandparents who are the child’s primary caregivers, stepparents, and families with other structures is needed since the sample for this study did not reflect the variety of families that are encountered in practice.

More studies that incorporate the element of change over time are needed, especially for the population of patients and families who spend weeks and months in the

hospital and may have multiple prolonged hospitalizations. These should examine families' trajectories at multiple time points, and should begin immediately after admission to provide a comparison to previous studies which were conducted early in the ICU stay. This may help determine if the differences in the findings from the present study are due to the different timing of data collection or if stressors identified in previous research (e.g., parental role uncertainty, environmental stressors) have been effectively addressed as a result of changes in ICU design and family-centered care delivery models. Additionally, it will be important to further explore the stress of an ICU hospitalization as it relates to a family's chronic illness phase, as there may be a difference in ICU-related sources and magnitude of stress for families who have been dealing with chronic illness for several months or years compared to those who are in the "crisis: initial adjustment period" described by Rolland (1997).

Since patients in the present study had been transferred to the general care unit at the time of the second phase of data collection, it was not possible to differentiate what role the length of hospitalization had in sources of stress and how they changed; differences in medical team composition and nursing staffing models may have played a more significant part than the LOS. A specific aspect that would be important to explore would be the stress of receiving mixed messages; does this become a source of stress over time regardless whether the child is in the ICU or on the general care unit? Patient satisfaction data used for quality improvement suggests that length of hospitalization may be a more important factor, but this has not been validated with research.

Implications for Theory

The ecological model that was developed for this research was based in previous PICU research and the investigator's experience working in this setting. Overall this model appeared to be supported by this research; the majority of individual and family factors appeared to play a role in families' stress. Some factors were not validated as sources of stress for participants in this sample, such as some environmental stressors (e.g., privacy, sounds, 24/7 lights). As discussed, this may be because data were collected after families had become accustomed to the environment; the design of the ICU likely influenced this as well. It is likely that some factors in the model, particularly those in the social-cultural and built environments, may be more relevant at different times in the hospitalization, some increasing over time and others becoming almost irrelevant. The "pull" between the ICU and home would be important to add if this is validated as a source of stress in future research.

Since a number of previous studies have focused on parent role alteration and the family-nurse boundary, a model that incorporates a broader range of factors will continue to be useful as future research is conducted. This will support exploration of the essence of family stress and relationships between variables within the complex system that the family represents.

Conclusion

This study offers a new way to consider family stress in PICU for families who stay in the hospital for two weeks or longer and whose children have ongoing health care needs. The findings reflect the changing face of PICU care, both in terms of family-

centered care delivery models and design, and illustrate the need to reconsider which factors identified in previous research are relevant, clarifying their contribution to stress for which families and at what points in their experience. Similarly, we need to validate and continue to explore newly identified sources of stress such as separation of the family unit and care-related team communication, as well as the role of pile-up of life events in the family's overall experience of stress in pediatric critical care. This will lead to knowledge about strategies for nursing assessment and intervention to address family stress in long-term pediatric critical care.

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Appendix A

Family Stress and Nurse Support in Pediatric Critical Care: A Pilot Study Summary

Aims

A pilot study was conducted with the following aims:

1. Collect preliminary information about family stress from families and nurses of children in the ICU.
2. Determine if the Family Inventory of Life Events (FILE), Family Systems Stressor-Strength inventory (FS³I), and/or Nurse Parent Support Tool (NPST) are useful instruments to answer the main study's research questions.
3. Pilot the data collection process (interview, FILE, FS³I, NPST, and brief chart review) with ICU families and nurses, including determining the amount of time that it takes for individuals to complete the FILE, FS³I, and NPST.
4. Determine the feasibility of this data collection with families of children in the ICU.

Participants and Procedure

Participants included two mothers of PICU patients (one with PICU length of stay three weeks, one with length of stay seven weeks) and two nurses (one consistent caregiver for each of these families). Each mother and nurse participated in individual semi-structured interviews followed by completion of the FILE, FS³I, and NPST. Nurses were asked to complete the instruments based on their perspective of the family's experiences.

Note: Family Inventory of Life Events (FILE) (McCubbin, Thompson & McCubbin, 1996). Family Systems Stressor-Strength Inventory (FS3I) (Berkey & Hanson, 1991).

Appendix B

Conceptual Model

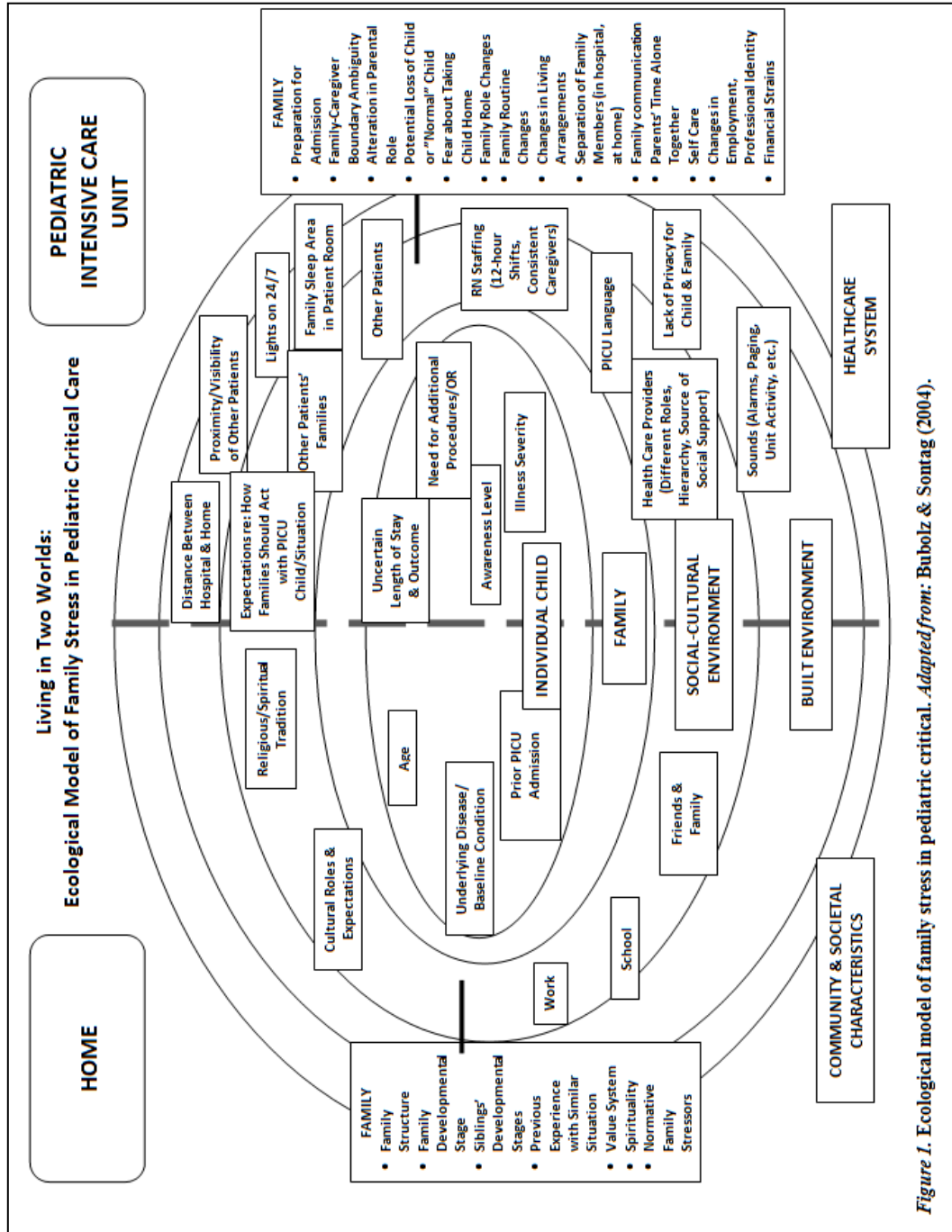


Figure 1. Ecological model of family stress in pediatric critical. Adapted from: Bubolz & Sontag (2004).

Appendix C

Literature on Family Stress in PICU

Table C1

Family Stress Studies in PICU

	Study aim	Design & data collection methods	Findings specific to family stress
Tomlinson, Peden-McAlpine & Sherman (2012)	Develop & test Family Systems Intervention to decrease family stress & uncertainty in PICU	2x2 mixed method design Instrument completion: Family Nurse Caring Belief Scale Family interviews, nurse interviews	<ul style="list-style-type: none"> Slight decrease in stress immediately after FSI; no statistically significant difference between groups Families: gratitude for nurse empathy, increased comfort in nursing presence, increased hope Nurses: greater awareness of family chaos & suffering, reframed preconceived ideas about families, began to incorporate family caring practices into care
Saied (2006)	Explore relationships between family & child demographic characteristics, stress, coping, social support, & adjustment in families who have a child in the PICU after heart surgery	Descriptive correlational cross-sectional design Self-administered questionnaire: FILE (intrafamily strain, stressful family life events), PSS:PICU, CHIP, ISSB, FAD (general functioning, communication)	<ul style="list-style-type: none"> Intrafamily strain (FILE subscale): 2.3 (SD 2.1) Stressful family life events (FILE subscale): 1.3 (SD 1.1) Both FILE subscales: positive association with general family functioning & communication Stressful family life events (FILE subscale) & coping pattern II (CHIP subscale: social support, self-esteem & psychological stability): negative association Social support moderated stress (PSS:PICU + FILE subscales), family adjustment Stressful family events: strongest predictor of communication (FAD subscale)
Peden-McAlpine, Tomlinson, Forneris, Genck & Meiers (2005)	Investigate effectiveness of Reflective Practice Intervention to increase family sensitivity in PICU nurses' practice	Phenomenology Intensive, open-ended individual interviews	<p>Themes:</p> <ul style="list-style-type: none"> Acknowledging & reframing preconceived ideas regarding families Recognizing meaning of family stress Beginning to incorporate family into nursing care
Tomlinson & Harbaugh (2004)	Develop & test Family Nurse Boundary Ambiguity Scale-Pediatric Intensive Care Unit (FNBAS-PICU)	Item generation & psychometric testing Instrument completion: FNBAS-PICU, PSS-PRAS, PPUS-PCF	<p>Reliability: .81 Concurrent validity: PSS:PRAS: .33 ($p=.000$); PPUS:PCF: .54 ($p=.000$) Sensitivity: child illness severity: $r = .20$ ($p = .02$); family est. of child's awareness: $r = -.31$ ($p = .000$); good admission preparation: $r = -.20$ ($p = .01$); frequency of previous PICU admit: no association Construct validity: 4 factors accounting for 59% of variance</p> <ul style="list-style-type: none"> Family affection & protection Family responsibilities & rights Family autonomy Family boundary maintenance

Family Stress Studies in PICU (continued)

	Study aim	Design & data collection methods	Findings specific to family stress
Board & Ryan-Wenger (2002)	Prospectively study long-term effects of PICU experience on parental perception of family functioning	3-group prospective, comparison study Instrument completion: FILE, FAM III, PSS:PICU, SCL-90-R	All groups: similar findings & changes over time (all measures) <u>Time 1:</u> All groups moderately stressed (PICU mothers' FILE: 597, mean) Positive correlation: family stress (FILE) & parent stress (PSS:PICU), stress symptom scores (SCL90-R) <u>Time 4:</u> Increase in family stress (FILE) from Time 1 (all groups) Positive association between stress symptom scores (SCL-90-R) & family functioning (FAM III), family stress (FILE) & PRISM Mothers with lower FILE at Time 4: worse family functioning over time
Tomlinson, Swiggum & Harbaugh (1999)	Identify health care provider actions to reduce stress related to the boundary interface between families & nurses	Part 1: Exploratory design to determine subjects' group membership Instrument completion (HRFBAS) Part 2: Descriptive design with qualitative methods Family interviews	HRFBAS scores (whole sample): 35-50 (range) Parents with high scores: 39.62 (mean) Parents with low scores: 28.28 (mean) Themes: <ul style="list-style-type: none"> • Fostering family normalcy: recognizing the child within, comforting/connecting, needing to know • Respecting family rights: informing/orienting, including • Strengthening family boundaries: trusting, planning, supporting
Mu & Tomlinson (1997)	Examine the essence of family stress perception by using a phenomenological approach to investigate the lived experience of parents when their child is admitted to a PICU	Phenomenology In-depth family interviews	Strong evidence of a collective perception of stress within the family; 4 realms: <ul style="list-style-type: none"> • Initial boundary ambiguity: global experience of crisis (themes: process experience, condition experience, expanding experience) • Parents' coping patterns: toward the child (participating); toward the sibling(s) (substitutive parenting); toward each other (mutual supporting) • Extrafamilial resources: external resources; information related to the child's condition; primary caregiver resources • Functioning of the family boundary: boundary maintenance (boundary transaction, boundary expansion, maintaining relationship with child)

Note. FILE=Family Inventory of Life Events. PSS:PICU=Parental Stressor Scale: PICU. CHIP=Coping Health Inventory for Parents. ISSB=Inventory of Socially Supportive Behaviors (shortened version used). FAD=Family Assessment Device. PSS:PRAS=Parental Stressor Scale: Parental Role Alteration Subscale. PPUS:PCF=Parental Perception of Uncertainty in Illness Scale: Parent-Child Form. FAM III=Family Assessment Measure III. SCL-90-R=Symptom Checklist-90 Revised.

Table C2

Theoretical Frameworks, Units of Interest, Units of Analysis

Authors	Framework(s) Definitions related to family stress	Unit of interest/unit of measure Measures (primary focus)
Tomlinson, Peden-McAlpine & Sherman (2012)	Family Health Systems Model <u>Family stress</u> : systemic response of the family as a unit; often related to loss/anticipated loss manifest as change in family function	Family/parents FNCBS, family interviews, RN interviews (family system)
Saied (2006)	McCubbin & McCubbin Resiliency Model of Family Stress, Adjustment, & Adaptation <u>Stress (conceptual definition)</u> : dimensions of environmental stress in the PICU & the stress arising from intra-family strain & negative family life events <u>Stress (operational definition)</u> : PSS:PICU rating + accumulation of stressful family life events & intra-family strain that happened prior to the illness stressor (FILE subscales)	Family/one parent per child FILE, CHIP, FAD (family system) PSS:PICU (parent) ISSB (all relationships)
Peden-McAlpine, Tomlinson, Forneris, Genck & Meiers (2005)	Referred to Tomlinson et al. Not reported	Family/NA RN interviews (family system)
Tomlinson & Harbaugh (2004)	Family Systems Theory Family-Nurse Boundary Ambiguity in PICU <u>Family boundary ambiguity in PICU</u> : existence of/potential for, uncertainty in how the family perceives its roles, rights & responsibilities when health-care providers must supplement core family caring roles	Family/parents FNBAS-PICU (parent-PICU child dyad)
Board & Ryan-Wenger (2002)	McCubbin & McCubbin Resiliency Model of Family Stress, Adjustment, & Adaptation Not reported	Family/mothers PSS:PICU, SCL-90-R (parent) FAM III, FILE (family system)

Theoretical Frameworks, Units of Interest, Units of Analysis (continued)

Authors	Framework(s) Definitions related to family stress	Unit of interest/unit of measure Measures (primary focus)
Tomlinson, Swiggum & Harbaugh (1999)	Referred to: Mishel's Uncertainty Theory Family Boundary Ambiguity Theory <u>Health-related family boundary ambiguity</u> : existence of uncertainty re: who is responsible for performing what essential caregiving tasks which can lead to disruption, stress, & conflict at the boundary interface between family & caregiving systems when core family caring roles must be supplemented by health care providers	Family/parents HRFBAS, family interviews (parent-child dyad)
Mu & Tomlinson (1997)	Symbolic Interactionism Family Systems Theory Not reported	Family/parents Family interviews (family system)

Note. Only frameworks related to family and/or family stress are included. FNCBS=Family Nurse Caring Belief Scale. PSS:PICU=Parental Stressor Scale:PICU. FILE=Family Inventory of Life Events. CHIP=Coping Health Inventory for Parents. ISSB= Inventory of Social Support Behaviors. FAD=Family Assessment Device. FNBAS-PICU=Family Nurse Boundary Ambiguity Scale: PICU. SCL-90-R=Symptom Checklist-90 Revised. FAM III=Family Assessment Measure III. HRFBAS=Health-Related Family Boundary Ambiguity Scale. (FNBAS-PICU and HRFBAS are the same instrument; titled differently in these studies.)

Appendix D

CONSENT FORM

Family Stress in Pediatric Critical Care

You are invited to be in a research study on the sources of stress that families experience when their children are hospitalized in the intensive care unit (ICU). We ask that you read this form and ask any questions you may have before deciding if you want to continue in the study.

This study is being conducted by Sandy Hagstrom, PhD(c), RN, CNP who is the advanced practice nurse leader for the pediatric intensive care unit (PICU) and cardiovascular intensive care unit (CVICU) at University of Minnesota Children's Hospital.

Background Information

The purposes of this study are to 1) describe sources of stress for families whose children require extended hospitalization in the PICU, and 2) explore how sources of stress change over time. This study is being conducted as part of the requirements to complete the researcher's doctoral degree at the University of Minnesota School of Nursing.

Parents of children hospitalized in the ICU will be invited to take part in this study.

Procedures

If you participate in the study, we will ask you to participate in an interview and complete two surveys at two points in time – after your child has been in the ICU for 1-2 weeks and 4-6 weeks later. At each of these times, you will be asked to:

- Participate in an interview about the sources of stress your family has experienced while your child is in the ICU. The interview and survey completion will take about 45-60 minutes and will be audio recorded.
- Complete the Family Inventory of Life Events (FILE) which is a list of 71 family life changes. To complete the FILE, you will choose "yes" or "no" to indicate if that change happened to anyone in your family in the past 12 months.
- Complete the Family Systems Stressor-Strength Inventory (FS³I), which is a list of 12 questions. To complete the FS³I, you will circle a number that best describes the influence your child's hospitalization in the PICU has on your family's life and how well you perceive your family's overall functioning. You may also write comments about each question.

Risks and Benefits of Being in the Study

This study has minimal risks. You can stop participation at any time, and if you have any uncomfortable feelings as you talk about your experiences, you may speak with a social worker. The researcher will collect information from your child's medical record. This means she will have access to private information.

There are no guaranteed benefits to participation, but you may find it helpful to be able to talk to someone about your feelings.

Compensation

You will not be paid to participate in this study.

Confidentiality

The records of this study will be kept private and the identifying information (e.g., name, diagnosis) will be kept separate from the completed surveys. In any sort of report we might publish, we will not include any information that will make it possible to identify a subject. Research records will be stored securely and only the researcher will have access to the records. Audio recordings will be destroyed after the study is completed.

Voluntary Nature of the Study

Participation in this study is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University of Minnesota Children's Hospital, Fairview Health Services, or the University of Minnesota. You are free to not answer any question or withdraw at any time without affecting those relationships.

Contacts and Questions

The researcher conducting this study is Sandy Hagstrom. You may ask any questions you have now. If you have questions later, **you are encouraged** to contact her at the hospital, 612-365-3165, shagstr1@fairview.org or her advisor Dr. Susan O'Conner-Von at the School of Nursing, 612-626-6606, ocon0025@umn.edu.

If you have any questions or concerns regarding this study and would like to talk to someone other than the researchers, **you are encouraged** to contact Fairview Research Administration, 2344 Energy Park Drive, St. Paul, MN, 55108; (612) 672-7692 or (866) 508-6961.

You will be given a copy of this information to keep for your records.

Statement of Consent:

I have read the above information. I have asked questions and have received answers. I consent to participate in the study.

Signature: _____ Date: _____

Signature of Investigator: _____ Date: _____

Appendix E

Family Background Data Collection Form

Marital status: _____

Who is in your family?

Name	Age	Relationship (husband, daughter, etc.)	Employment and/or grade in school	Currently staying where

Where do you and your family live? _____

How far is your home from the hospital? _____

Have you or any members of your family temporarily moved closer to the hospital? _____

If yes, how long ago? _____

Was your child's admission to the ICU planned? _____

Appendix F

Interview Guide – Time 1

1. Tell me about the things that make this experience (having your child in the ICU) stressful for your family.
2. Completion of Family Inventory of Life Events (FILE) with subsequent discussion of additional thoughts stimulated by FILE completion.
3. Completion of Family System Stressor-Strength Inventory (FS³I) with subsequent discussion of additional thoughts stimulated by FS³I completion.

Additional questions to ask if they don't emerge during the interview or instrument completion:

4. How has this situation affected:
 - a. Time you spend together as a couple (without other people around)?
 - b. Your role as a parent (to your child who's in the hospital)?
 - c. Your time/ability for "self care"?
5. To what extent is your family bothered by:
 - a. How your family and the nurses and other hospital staff work together in caring for your child?
 - b. Thinking about your child's future and whether he/she will be able to do "normal" things?
 - c. Thinking about what it will be like to take your child home?
 - d. The ICU environment? (Physical aspects, people, culture of the ICU)
6. To what extent do your spiritual beliefs and values affect how your family is dealing with this situation?
7. What other things do you think are important for me to know about your family's experience?

Appendix G

Interview Guide – Time 2

1. Tell me about how sources of stress are the same or different for your family since the last time we talked.
2. During our last conversation, you talked about [theme]. Would you say that it has changed? If so, how? [Repeat for each major theme identified at Time 1.]
3. Are there additional sources of stress that you have experienced since we last talked?
4. Completion of Family Inventory of Life Events (FILE) with subsequent discussion of additional thoughts stimulated by FILE completion.
5. Completion of Family System Stressor-Strength Inventory (FS³I) with subsequent discussion of additional thoughts stimulated by FS³I completion.
6. What other things do you think are important for me to know about your family's experience?

Appendix H

Approval Letters and Instrument Permission

UNIVERSITY OF MINNESOTA

Twin Cities Campus

*Human Research Protection Program
Office of the Vice President for Research*

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September 23, 2014

Sandra Hagstrom
Unit 3 - PICU/CVICU
2450 Riverside Avenue
Minneapolis, MN 55454

RE: "Sources of Family Stress in Pediatric Critical Care: A Mixed Methods Study"
IRB Code Number: **1407P52583**

Dear Ms. Hagstrom

The Institutional Review Board (IRB) received your response to its stipulations. Since this information satisfies the federal criteria for approval at 45CFR46.111 and the requirements set by the IRB, final approval for the project is noted in our files. Upon receipt of this letter, you may begin your research.

IRB approval of this study includes the consent form received July 24, 2014 and recruitment received September 19, 2014.

The HIPAA Authorization received July 24, 2014 has been approved.

The IRB would like to stress that subjects who go through the consent process are considered enrolled participants and are counted toward the total number of subjects, even if they have no further participation in the study. Please keep this in mind when calculating the number of subjects you request. This study is currently approved for 25 subjects. If you desire an increase in the number of approved subjects, you will need to make a formal request to the IRB.

For your records and for grant certification purposes, the approval date for the referenced project is September 5, 2014 and the Assurance of Compliance number is FWA00000312 (Fairview Health Systems Research FWA00000325, Gillette Children's Specialty Healthcare FWA00004003). Research projects are subject to continuing review and renewal; approval will expire one year from that date. You will receive a report form two months before the expiration date. If you would like us to send certification of approval to a funding agency, please tell us the name and address of your contact person at the agency.

As Principal Investigator of this project, you are required by federal regulations to:

*Inform the IRB of any proposed changes in your research that will affect human subjects, changes should not be initiated until written IRB approval is received.

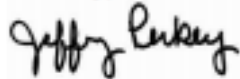
Driven to DiscoverSM

- *Report to the IRB subject complaints and unanticipated problems involving risks to subjects or others as they occur.
- *Inform the IRB immediately of results of inspections by any external regulatory agency (i.e. FDA).
- *Respond to notices for continuing review prior to the study's expiration date.
- *Cooperate with post-approval monitoring activities.

Information on the IRB process is available in the form of a guide for researchers entitled, What Every Researcher Needs to Know, found at <http://www.research.umn.edu/irb/WERNK/index.cfm>

The IRB wishes you success with this research. If you have questions, please call the IRB office at 612-626-5654.

Sincerely,



Jeffery Perkey, MLS, CIP
Research Compliance Supervisor
JP/bw

CC: Administration Fairview Research, Susan O'Conner-Von

UNIVERSITY OF MINNESOTA
MEDICAL CENTER
 FAIRVIEW

Riverside Campus
2450 Riverside Avenue
Minneapolis, MN 55454

May 27, 2014

Sandy Hagstrom
PICU/CVICU – Amplatz Children’s Hospital
2450 Riverside Avenue
Minneapolis, MN 55454

Dear Ms. Hagstrom,

Thank you very much for submitting your research proposal titled “Sources of Family Stress in Long-Term Pediatric Critical Care: A Mixed Methods Study.”

Your proposal has been approved.

When you receive your IRB approval, please forward a copy to me. I have included an extra copy of the approval letter, so you may forward it to the IRB.

When you have completed your research, forward a copy of your report to the Nursing Research Council. You can do that by sending it me. We also request that you support research dissemination by contributing a copy of your abstract for the Nursing Links (Nursing Department newsletter for University of Minnesota Medical Center, Fairview). We also may want to interview you for an internal Fairview publication.

Good luck on your research! This is exciting work and is definitely needed for Nursing!

Sincerely,

Shamsah Rehmatullah, RN, ACNS-BC
Chair, Nursing Research Council Proposal Review Subcommittee



UNIVERSITY
of HAWAII
MĀNOA

Myron B. Thompson School of Social Work

January 2, 2013

Sandra Hagstrom
PhD Student
School of Nursing
University of Minnesota

Dear Sandra Hagstrom

The purpose of this correspondence is to confirm permission for your use of File: Family Inventory of Life Events and Changes.

We wish you the best

Let us know if we can be of assistance.

Sincerely,

A handwritten signature in black ink, appearing to read 'Hamilton I. McCubbin'.

Hamilton I. McCubbin Ph.D.
Professor and Director of Research
Center for Training, Evaluation and Research of the Pacific

CC: Dr. Laurie McCubbin
CC: Dr. Jason Stevers

7/29/2015

University of Minnesota Mail - Shirley to Sandy:: Request to Use Family Systems Stressor-Strength Inventory



Sandra Hagstrom <hagst063@umn.edu>

Shirley to Sandy:: Request to Use Family Systems Stressor-Strength Inventory

3 messages

Shirley Hanson <hansonshirley@comcast.net>

Tue, Mar 5, 2013 at 10:23 PM

To: hagst063@umn.edu

Cc: "Coehlo, Deborah" <debbie@juniperpediatrics.com>, "Hanson, Shirley" <hansonshirley@comcast.net>, "Rowe Kaakinen, Joanna" <jrowe@linfield.edu>, "Steele, Rose" <rstele@yorku.ca>, "Tabacco, Aaron" <atabacco@gmail.com>

Dear Sandy,

Thank you for your interest in the Family Systems Stressor-Strength Inventory. Congratulations on your dissertation topic. Someday perhaps you will publish your findings in the JOURNAL OF FAMILY NURSING(JFN).

You have my permission to use Part II of the FS3I in your research. The instrument has been used previously for research purposes but I have not kept track of where or when since I retired 10+ years ago. You will find references pertaining to this instrument in the book FAMILY HEALTH CARE NURSING: THEORY, PRACTICE AND RESEARCH(FA Davis, 2010). I founded that book many years ago, and it will be coming out in its 5th edition fall 2013/winter 2014. Dr. Joanna Kaakinen is now the first editor of that book. I am copying your request to the other members of the current writing team.

Look at JFN Feb 2013(page 122) and you will see a photo of the editors for the 4th edition of that same book.

Please feel free to call me if I can be of any assistance.

Sincerely,

Shirley Hanson

Dr. Shirley M.H. Hanson
RN, PhD, PMHNP/ARNP, FAAN,CFLE, LMFT
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Appendix I

Child and Family Demographics

Table I

Patient and Family Demographics

Child age	Primary medical diagnosis & co-morbidities	Reason for ICU care	Planned	ICU LOS (hospital LOS)	Parent ages	Other family members	Distance from home to hospital
12 days	Complex congenital heart defect Co-morbidities: trisomy 21, acute respiratory failure	Postop cardiac surgery; mechanical ventilation; critical drips & monitoring	Yes	10 days (12 days)	31/36	No siblings	6 miles
9 days	Coarctation of aorta Co-morbidities: complex congenital heart disease	Critical drips & monitoring	Yes	8 days (9 days)	34/35	1 preschool, 1 teen sibling	85 miles (2 hours)
12 years	Respiratory failure; viral infection Co-morbidities: cancer (2011), cancer metastasis (2013); anxiety; neurologic event (2014)	Respiratory failure	No	10 days (10 days)	48/53	1 teen sibling	77 miles
3 months	Acute respiratory failure; septic shock Co-morbidities: history of congenital heart defect repair; laryngomalacia; aspiration; G-tube	Respiratory failure	No	14 days (14 days)	33/33	2 preschool siblings	15 miles (20 minutes)

Patient and Family Demographics (continued)

Child age	Primary medical diagnosis & co-morbidities	Reason for ICU care	Planned	ICU LOS (hospital LOS)	Parent ages	Other family members	Distance from home to hospital
18 months	Ventriculoperitoneal shunt infection Co-morbidities: history of brain cyst; seizures	Externalized ventricular shunt	No	8 days (8 days)	32/32	No siblings	70 miles
18 years	Dehydration; respiratory failure; systemic inflammatory response syndrome; acute respiratory distress syndrome Co-morbidities: metabolic disease; seizures	Mechanical ventilation, critical drips & monitoring	No	7 days (7 days)	52/50	4 young adult siblings, sister-in-law, 3 preschool nieces/nephews	15 miles (20-30 minutes)
11 years	Transplant Co-morbidities: small bowel obstruction; diabetes	Critical drips & monitoring; intensive dressing change with anesthesia	Yes	<u>Time 1:</u> 17 days (17 days) <u>Time 2:</u> 21 days ICU, 18 days GCU (39 days)	41/36	1 school age, 1 young adult sibling	1200 miles (19+ hrs)
5 months	Complex congenital heart defect Co-morbidities: Trisomy 21, pulmonary hypertension	Postop cardiac surgery; critical drips & monitoring	Yes	<u>Time 1:</u> 8 days (8 days) <u>Time 2:</u> 36 days ICU, 5 days GCU, 6 days ICU, 2 days GCU (49 days)	31/35	1 preschool sibling	25 miles (45 minutes)

Note. ICU: intensive care unit; LOS: length of stay; GCU: general care unit.

Appendix J

FILE Data

Table J1

FILE Scores and Subscores Prior to this Illness/Hospitalization (Sorted by Family Stage, then Total Score)

Family	Family stage	Total score	Comparison to norm for family stage	Intrafamily strains	Marital strains	Pregnancy, childbearing strains	Finance, business strains	Work-family transitions, strains	Illness, family "care" strains	Losses	Transitions "in & out"
1	Preschool	114	Low	0	0	0	19	95	0	0	0
8	Preschool	189	Low	97	0	50	42	0	0	0	0
4	Preschool	208	Low	36	0	50	23	55	44	0	0
2	Adolescent	108	Low	0	0	0	19	51	0	0	38
3	Adolescent	441	Moderate	227	58	0	0	0	156	0	0
6	Launching	482	Moderate	36	0	50	70	235	0	0	71
7	Launching	826	Moderate	420	58	0	150	77	93	0	28
Mean	–	356	–	117	15	19	43	80	52	6	22

Note. For families of newborns admitted to the ICU immediately, “gave birth to or adopted a child” (50 points) in the “pregnancy and childbearing strains” was NOT included as baseline stress. This is reported in Aim 2 as a change. The FILE category “Family Legal Violations” is not included in this table as all families scored 0 for this subscore. Family 5 is not represented in this table since data are not available.

Table J2

Change in FILE Scores in Relation to This Episode of Care (Ordered by Amount of Change in Total Score)

Family	Change pre-hospital to Time 1 (% increase)	Pre-hospital score & category	Time 1 Score & category	Subscales with change in order of highest to lowest (# of points)	Primary stressor identified at Time 1	Planned admit (ICU LOS)
3	51 (12%)	441 Moderate	492 Moderate	Intrafamily strains (51)	Separation	No (10 days)
1	85 (75%)	114 Low	199 Low	Pregnancy & childbearing (50) Illness & family “care” strains (35)	Unknowns	Yes (10 days)
4	121 (58%)	208 Low	329 Moderate	Intrafamily strains (86) Illness & family “care” strains (35)	Separation	No (14 days)
7	158 (19%)	826 Moderate	984 High	Finance and business strains (60) Work-family transitions & strains (51) Illness & family “care” strains (47)	Setbacks	Yes (17 days)
6	214 (44%)	482 Moderate	676 Moderate	Intrafamily strains (121) Illness & family “care” strains (93)	Child’s discomfort and agitation	No (7 days)
2	224 (207%)	108 Low	332 Moderate	Intrafamily strains (97) Pregnancy & childbearing (50) Transitions “in and out” (42) Illness & family “care” strains (35)	Separation	Yes (8 days)
8	419 (222%)	189 Low	608 Moderate	Intrafamily strains (220) Illness & family “care” strains (75) Work-family transitions & strains (51) Transitions “in & out” (42) Finance and business strains (31)	Separation, unknowns	Yes (8 days)
5	–	–	476 Moderate	–	Food, distance from home	No (8 days)

Note. Pre-hospital FILE data are not available for family 5. ICU: intensive care unit. LOS: length of stay. Category per norms is based on family stage.

Appendix K

Table K

Comparison of Themes from Time 1 and Time 2

Time 1 Themes and Subthemes	Time 1 Subthemes Still Present at Time 2 (Change in Amount and/or Emphasis at Time 2)
Separation	
Being apart	Present (decreased)
A constant pull	Present (decreased)
Family role changes	Absent
Leaving the hospital	Present (emphasis on different factors leading to trust)
Siblings at the hospital	Present (enhanced incorporation of siblings into hospital)
Not knowing	
Unknowns	Present (decreased)
We thought we were prepared	Absent
The roller coaster	Absent
Child's illness and distress	
Child's distress	Absent (all subthemes)
Critical illness	
Ongoing health care needs	
Care and caring	
When they're not on the same page	Present (significantly increased for 1 family, now primary source of stress)
Listening to parents	Absent
Availability of the team	Present (not source of stress)
It depends on the nurse	Present (increased for 1 family, decreased for another; emphasis on different factors)
Continuity and fit	Present (increased, emphasis on different factors)
Genuine caring for the child and family	Present (increased for 1 family, decreased for another)
Emotional stress	
Fathers' stress	Present (same)
I don't want to talk about it	Absent
Physical stress	
Sleep	Absent, all subthemes except "self care" (emphasis on hospital resources)
Activity and nutrition	
Self care	
My husband makes sure I take care of myself	
Job and financial stress	
Job flexibility and benefits	Present (increased for 1, decreased for another)
Financial strains	
What we've been through before	
We had practice	Absent, all subthemes except "ongoing healthcare needs" (emphasis on team's recognition of current episode in context)
Baseline stress	
Ongoing healthcare needs	

