

PARENTAL STRESS AND COPING DURING THE HOSPITALIZATION OF A CHILD

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A dissertation submitted to the faculty at the University of North Carolina at Chapel Hill in partial fulfillment of the requirements for the degree of Doctor of Philosophy in the School of Nursing.

Chapel Hill  
2015

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## ABSTRACT

CAROLYN W. JONES: Parental Stress and Coping during the Hospitalization of a Child  
(Under the direction of Mary R. Lynn)

**Background:** Having a child hospitalized in an intensive care unit is a stressful experience for parents. Some parents choose to write about their experiences in publically available weblogs posted on the Internet. These blogs can provide rich insight into the stressors encountered by families with an ill child, and how they use their emotional and physical resources to cope with those stressors.

**Method:** Using the Transactional Model of Stress and Coping as a framework, 20 blogs written by parents while their child was hospitalized were identified using purposive sampling techniques. The blogs were analyzed using thematic narrative analysis, looking for stressors identified by the parents as well as ways they coped with the stressors. The following four research questions were addressed: (1) What stressors do parents report in blogs? (2) What coping strategies are identified by parents? (3) How do the stressors and coping strategies described by parents change over the course of their infant or child's hospitalization? and, (4) Is there evidence in the blogs to support or challenge the supposition that secondary appraisal leads to problem- and emotion-focused coping strategies?

**Findings:** Analysis demonstrated the identification of stressors and coping strategies within the text of the blogs. Five categories of stressors were found in the narratives: child-related, hospital-related, information, parenting, and self. Both emotion-focused and problem-focused categories of coping mechanisms were discovered. Emotion-focused techniques were

used most often and categories included accepting, avoiding, maintaining hope, reframing, utilizing logic, and valuing. Problem-focused coping strategies included creating, providing, seeking and taking. These strategies were more often used later in the hospitalization and often in response to child-related stressors. Early in the hospitalization, parents described multiple stressors with no coping response documented. As the hospitalization progressed, identification of a stressor was more likely to be followed directly by a behavior or event, which appeared to be a coping strategy. The blog author's appraisal and reappraisal of stressors was often implicit in the text, therefore it was difficult to isolate.

**Conclusions:** Blogs provided a rich source of information related to stressors encountered by parents while their child was hospitalized, as well as ways they coped with those stressors. This information can lead to a deeper understanding of the experiences of families with a sick child, and to the development of ways to help parents cope. Improved coping can lead to better outcomes for families who experience the critical illness of a child.

Dedicated to Max and Peggy

## ACKNOWLEDGEMENTS

Thank you isn't an adequate expression of the appreciation I feel for Dr. Mary Lynn. She was the perfect mentor for me and understood how to keep me motivated, and I would not have made it through this process without her support. I would also like to thank the members of my committee for their support and patience as I slowly made my way through this process.

The journey has been long, and I never could have completed it without the help and support of many. First of all, my parents, Max and Peggy West. They always believed in me and helped me believe in myself. I'm sorry that they didn't live to see me finish, but I felt their encouragement to the end. My husband, Jeff, and my children, Weston, Will, and Natalie were always cheering me on and understanding when I couldn't be there for every event. Their love and support kept me going when I wanted to stop.

I also want to acknowledge the "First Year Supper Club" made up of my fellow doctoral students at UNC, especially Brandy Mechling, Britt Pados, Ashley Leak, and Kobie Lieper. We were there to support each other, and remind each other of the important things: Never underestimate the power of the semicolon and don't forget to click on the running man. Our dinners together meant so much to me as we discussed school and life.

To all the nurses, nurse practitioners, and neonatologists that I have worked with while in school, I say thank you for asking me how it was coming along, and not judging as the time stretched on (with a special thanks to Tracy Johnson and Cheryl Smith). Also thanks to the faculty and students at UNCW who have continued to cheer me on.

My acknowledgements would not be complete without recognizing Starbucks for their contributions to my research. They kept me awake on the long drive to Chapel Hill (thanks to the crew at the I-85 exit 76 drive-thru). They hosted many work sessions where Dr. Lynn taught me to think and to believe in myself. And they helped me work late into the night when I pushed up against (or past) a looming deadline.

One last thank you --- to the families of babies and children who are in the hospital. You teach me every day about resilience and hope in the face of crisis, and remind me of what is really important in life. In the words of my friend Kathy Kent Nesbitt in speaking of her daughter Julia's ongoing illness "if love could cure she would never be sick."

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## CHAPTER 1

### Introduction

Having a child or infant in the hospital is one of the most stressful events parents can experience. They may be overwhelmed with the stress of the illness, complicated medical information, and worry for their child's future while trying to balance other family demands and maintain some continuity in their daily lives. As they encounter stressors, they must find ways to cope and harness resources to maintain stability. The Transactional Model of Stress and Coping provides a framework for the study of the process of stress appraisal and subsequent coping efforts. This model emphasizes the interaction between an individual and their environment with coping viewed as a process.

A relatively new social media phenomenon is the use of blogs to write about personal experiences. A weblog provides a format in which an individual articulates his/her thoughts in a time-sequenced manner to create an Internet-based journal. The prevalence of blogs about either patients or their family member's experiences with illness has increased dramatically in recent years (O'Brien & Clark, 2010); many parents are writing about their experiences when their child is hospitalized (Heilferty, 2011). There is little research on these online narratives of the family's experience of illness, yet they represent a potentially rich source of information for healthcare providers to learn about what families go through when in such situations. The purpose of this study was to use narrative analysis techniques to analyze illness blogs authored

by parents of an infant or child hospitalized in an intensive care unit to identify stressors perceived by the parents and measures used by them to cope with these stressors.

## **Background**

When a child is hospitalized, parents are concerned about their child's eventual outcome and if there will be any long-lasting consequences. There may be uncertainty as to what caused the illness, shock about the gravity of the situation, or guilt if the hospitalization was due to an accident or something perceived as having been under the parents' control. Usual routines are disrupted and they may feel isolated, even if family members and friends surround them. Often they have to sort through large volumes of unfamiliar medical and/or diagnostic information, yet they may have to make decisions based on their incomplete understanding. To do this, they must trust the medical professionals, who they may not have known prior to this situation. In short, they are placed in an unfamiliar, unexpected, unwanted and frightening environment.

Having a hospitalized child causes disequilibrium within the family's structure and function. Researchers have identified this disruption as a source of stress for families (Board & Ryan-Wenger, 2002; Graves & Ware, 1990; Landolt, Vollrath, Ribbi, Gnehm, & Sennhauser, 2003; Long, 2003; Miles & Carter, 1982), which may influence how they adjust to their new situation (Katz, 2002; LaMontagne, Hepworth, Johnson, & Desphande, 1994; Noyes, 1999). When a child is hospitalized, everyday life is interrupted, and potential stressors can range from wondering whether their child will survive to who is going to take care of routine daily chores.

Stresses experienced by individuals during the acute illness of a family member are profound and adverse health and psychological consequences may occur as a result (Franck et al., 2015; Schulz & Beach, 1999). Brehaut et al. (2009) demonstrated that caregivers of children with health problems were twice as likely to report chronic health conditions, depressive

symptoms, and poorer general health than caregivers of healthy children. In a more recent study, Muscara et al. (2015) reported that half of the parents of a child hospitalized with a life threatening illness met criteria for acute stress disorder and increased rates of depression and anxiety. It is important for nurses to better understand what parents identify as stressful during their child's hospitalization as well as potential coping strategies in order to help them avoid the negative consequences of stress.

### **Conceptual Framework**

The concept of stress is of great interest to researchers in many disciplines within the social and biological sciences. Interest in research about stress began with the impact of the early 20<sup>th</sup> century wars. Soldiers once exposed to war were noted to have symptoms ranging from diffuse anxiety to debilitating distress. These symptoms were initially attributed to the effects of loud explosions on the brain, with a psychological association then suspected when it was noted that it was not predictable in terms of who would be most affected (Lazarus, 1999).

Over time it was noted that symptoms of stress were present not only in wartime but also in times of peace, and took place in a variety of settings including home, work, and school. In the 1950's and 1960's, research on stress was conducted by researchers from many disciplines. Psychology research abandoned the positivist doctrine of behaviorism for value-expectancy theory, which emphasizes subjective meaning. Lazarus's first monograph related to stress and coping (1966) focused on his formulation of a theory of psychological stress based on the idea that stress and emotion are influenced by how a person appraises their transactions with the environment, leading to the development of the Transactional Model of Stress and Coping (TMSC) (Lazarus and Folkman, 1984). Subsequent research and refining of the TMSC

followed, along with development of a measurement tool, the Ways of Coping Questionnaire and Interview (Lazarus, 1999).

The TMSC provides a framework for explaining the process of appraising and coping with stressful events, and the interplay between the environment, resources, and strategies used for coping on the outcome of these events. Stress is conceptualized as the result of a transaction between a person and their environment that the person appraises as taxing or exceeding their resources (Lazarus & Folkman, 1984). Key concepts and operational definitions of the TMSC are summarized in Appendix A.

Stressors are the events or circumstances that a person perceives to exceed their resources and threaten their well-being (Schneider, 2008). Stressors can be internal or external, and include actual as well as perceived threats. Internal factors include such things as demands placed on one's self. External factors include a variety of different aspects including demands from others, physical resources, and constraints placed on an individual by the environment (Byers & Smyth, 1997; Matthieu & Ivanoff, 2006).

Cognitive appraisal is the process of evaluating the significance of an event or situation to determine whether it exceeds their resources. It is a two-step process that begins with the primary appraisal. An individual classifies an event as irrelevant, benign, positive, or stressful depending on their perception of the potential effects of the event on their well-being (Lazarus, 1999, Picci et al., 2015). Different individuals may classify the same event differently depending on the meaning of the event to them and the resources they have available. Once an event has been classified as stressful, a secondary appraisal occurs in which potential coping options are considered (Strom & Kosciulek, 2007). Reappraisal of the stressor is ongoing, and is influenced

by the perceived success or failure of coping strategies, new information regarding the stressor, or a change in resources available for coping (Honey, Morgan, & Bennett, 2003).

Coping, a multidimensional process referring to how individuals deal with stress, involves conscious cognitive and/or behavioral efforts to deal with events appraised as stressful, or exceeding the resources of the individual (Lazarus, 1999). The two types of coping are problem-focused coping and emotion-focused coping. Problem-focused coping serves to manage or directly change the source of the stress, while emotion-focused coping involves strategies directed at regulating the individual's emotional response to the stress (Shaw, 1999; Smith, SteelFisher, Salhi, & Shen, 2012). An individual can apply either or both types of coping to a situation. Coping is a dynamic process rather than a static trait, and changes over time and with reappraisal (Lazarus & Folkman, 1984).

Assumptions of the model include the following:

1. Emotions occur as a result of a specific encounter between a person and the environment, and each exerts reciprocal influence on the other (transactions);
2. Cognition and emotion are continuously changing (process);
3. The meaning of a transaction is derived from the context of the person and the environment (context);
4. Coping is comprised of constantly changing efforts (cognitive and behavioral) to manage demands (external and internal) that are determined to be taxing or exceeding the individual's resources;
5. The ability of a stressor to tax the resources of a person (appraisal) varies between individuals;



6. External support(s) can buffer stress by reducing its threat or by providing additional resources for coping.

Parents who have an acutely ill infant or child who is hospitalized experience a wide range of stressors (Seideman et al., 1997; Sweet & Mannix, 2012). Multiple stressors have been identified by researchers, including the appearance of the child (Balluffi et al., 2004; Board & Ryan-Wenger 2003), alteration in the role of the parent (Aamir et al., 2014; Board & Ryan-Wenger, 2002; Miles & Mathes, 1991), financial burden (Long, 2003), and the emotions of the child (Haines, Perger, & Nagy, 1995; Jee et al., 2012). Potential events such as uncertain outcomes and the possibility of the death of the child were also identified as stressors by parents (Balluffi et al., 2004; Jee et al., 2012; Youngblut & Jay, 1991).

Within the framework of the TMSC, parents appraise the life event of having their child or hospitalized and determine what events outweigh their emotional and physical resources. The parent's interpretation of an event is central to the model, and accounts for different responses among parents in similar situations. They then begin the process of using either emotion-focused or problem-focused methods for coping with the stressors, followed by a reappraisal of the events (Lin, 2009).

### **Narratives and Illness**

A narrative is a story that occurs when one or more individuals recount an event or experience. Ochs and Capps (2001) defined personal narrative as the use of language to give logical and temporal order to life events, and a way of attempting to bring meaning to the events by connecting them to the past, present, and future. Personal narratives can be formal or informal, begun with the ending in mind or continuing to unfold as new events occur, and is

written or verbalized. Studying the stories of others provides a way to understand their lives and experiences (Sandelowski, 1991).

Variation exists among researchers regarding what constitutes a narrative suitable for analysis. Riessman shared her concern that if the definition of a narrative is too broad, it could include anything, and if it is overly restrictive then valid units of analysis could be excluded (1993). Experts in narrative analysis agree that the narrative should be a discreet unit with a beginning and an ending or some sort of recognizable boundaries, as well as have a sense of coherence (Labov & Waletzky, 1997; Riessman, 2008; Wells, 2011). Narratives should have a chronological ordering of the events through time (Kelly & Howie, 2007; Ochs & Capps, 2001; Patterson, 2008; Riessman, 1993), should be logical to the storyteller and have meaning (Frank, 1995; Lai, 2010; Langellier, 1989; Ochs & Capps, 1996; Sandelowski, 1991).

“Narrative analysis” can represent multiple qualitative approaches that focus on the stories of individuals or groups. The important features of narrative analysis are that the focus of the investigation is the story – how it is structured and what meaning it has for the storyteller(s) (Polkinghorne, 1988; Riessman, 1993; Tamboukou, 2008). As the text is deconstructed into segments for categorization, the context of the original story must be maintained (Ayres & Poirier, 1996).

Narratives suitable for analysis can come from many sources, including life records, diaries, letters, and other forms of personal communication (Jones, 2000). As the Internet has evolved, its use has transitioned from a source for obtaining information to a participatory environment where individuals create stories and interact with others. Users of the Internet often organize into groups or networks, often with like interests or purposes (Colineau & Paris, 2010).

Social networking can occur via a number of different platforms, each offering their own pluses and minuses related to how they are structured (Baym, 2010).

One platform for social networking is the web log, or “blog,” a format in which an individual articulates thoughts or ideas in a time sequenced manner, creating an online diary or journal. Like a journal, separate entries are made by the author at a frequency of their choice. These individual entries are referred to as posts and are generally displayed in reverse chronological order with the most recent posting appearing first; as the reader continues through the blog they are moving backward in time. Most blogs include a place called a forum where the readers of the blog can make comments or enter a discussion. Communication via this forum occurs in an asynchronous fashion; messages are placed on the forum without the expectation of an immediate or even any response. Blog postings and comments are typically retained on the blog (archived) and can be viewed at any time. Some blogs are publicly available, and others require a password to access (Rettberg, 2008).

Although many different Interest-based varieties of blogs exist, illness blogs are the type of blog that is of particular interest to this study. In these blogs, a patient or proxy posts at intervals ranging from multiple times per day to weekly or even less often. These posts are often updates of the patient’s condition but also include information regarding the emotions of the blogger and challenges the family is facing. Heilferty (2009) defines illness blogs as “electronic narratives created by individuals affected by the experience of illness, either personally or by the illness of a loved one” (p. 1545). Many illness blogs contain links to other blogs of patients with similar conditions.

Illness blogs are often set up as a way of disseminating information to family and friends, although there may be a variety of reasons why bloggers choose to express themselves in this

manner. The interactive nature of these blogs sets up the possibility of support gained through expanding one's social network. Ties maintained by members of a social network, whether face-to-face or online, can vary from weak to strong. This is determined by factors such as the frequency of contact, type and duration of the relationship, and types of exchanges (Haythorwaite, 2005). Strong ties between individuals are important, as our family and close friends are willing to share their information and resources with us. Weak ties --- the connections with individuals we know but are not close friends with --- offer us access to different information and resources as these people are in different social circles from us (Granovetter, 1983; Koteyko, Hunt, & Gunter, 2015). The Internet offers an opportunity for new weak and strong ties to develop (Haythorwaite, 2005).

Illness blogs generally fit with the characteristics of a narrative, as they are chronological and have meaning to the storyteller. As for boundaries, they do not necessarily have an ending as they may be ongoing, but have a beginning point identified by the author's commencement of writing. This may or may not coincide with the actual start of the event. Since illness blogs present a story, the narrative analysis framework is a good fit for this study. Several typologies of narrative analysis have been proposed; the approach for this study will be a combination of thematic and visual analysis as described by Riessman (2008). With the thematic approach, the content of the story is most important, and the development of themes can be guided by existing theory (in this case identification of stressors and coping strategies). Additional information about the blogger was sought through their use of visual elements to further tell their story and describe their experience as well as the responses generated by readers of the blog. It should be noted that inter-subjective relationships develop as the researcher attempts to understand the

subjective viewpoint of the narrator, even in the absence of direct contact between the researcher and the narrator (Maynes, Pierce, & Laslett, 2008).

### **Problem Statement**

Parents who experience the hospitalization of an infant or child report that it is one of the most stressful experiences of their life, imposing multiple and varied stressors on the whole family (Seideman et al., 1997; Shudy et al., 2012). Blogs written by parents while their child is hospitalized due to injury or illness can provide a rich description of how parents appraise and cope with stressful events and potentially create a network of supportive social ties. With the TMSC as a framework, the purpose of this study was to use narrative analysis techniques to analyze illness blogs authored by parents of an infant or child hospitalized in an intensive care unit to identify stressors perceived by the parents and measures used by them to cope with these stressors.

### **Research Questions**

1. What stressors do parents report in blogs?
2. What coping strategies are identified by parents?
3. How do the stressors and coping strategies described by parents change over the course of their infant or child's hospitalization?
4. Is there evidence in the blogs to support or challenge the supposition that secondary appraisal leads to problem- and emotion-focused coping strategies?

### **Summary**

When a child is hospitalized the parent are stressed from being placed in an unfamiliar physical environment, bombarded with information, and having to make potentially life-altering decisions. The TMSC provides a framework understanding the appraisal of stressors by parents

of an ill child, and identifying coping strategies used as they deal with this stressful situation.

Some parents use the Internet as a vehicle for sharing their stories regarding their child's illness.

Analysis of the content of these blogs can yield information related to how parents evaluate the stressors related to their child's illness and hospitalization, and coping strategies they use to maintain stability.

## CHAPTER 2

### Overview

Advances in technology and medical science have dramatically improved the odds of survival of infants born prematurely or with other complications. Infants who, in the past, would not have survived now survive and even thrive, but to do so often experience prolonged hospitalizations (Charchuk & Simpson, 2005). Roughly 8-10% of all infants born in the United States are admitted to the Neonatal Intensive Care Units (NICU) for a variety of reasons, including prematurity, respiratory distress, sepsis, and congenital disorders and anomalies. These admissions to the highly technical world of the NICU often are a surprise to the parents and extended family, who are then faced with many unknowns as they are placed in this unfamiliar and unexpected situation (McCormick, Escobar, Zheng, & Richardson, 2008). Similar advances in diagnostics and medical treatment for childhood diseases and trauma have led to the increased use of mechanical ventilation and other therapies to sustain pediatric patients in specialized Pediatric Intensive Care Units (PICU) (Briassoulis, Flippou, Natsi, Mavrikiou, & Hatzis, 2004; Epstein & Brill, 2005).

The acute hospitalization of a child potentially affects the functioning and daily life of parents and other family members and can lead to adverse psychosocial outcomes for the family (Klassen et al., 2008). The usual process of being a parent can be interrupted or complicated by having their infant or child remain in the hospital for a prolonged period of time. Families

experience difficulties in carrying out day-to-day activities, and these difficulties can extend beyond the hospitalization of their child. Stress that develops in response to having an ill, hospitalized child can develop into an acute stress disorder or even progress to posttraumatic stress disorder. Chronic conditions often develop in premature and ill infants, and coping with these diagnoses can be disruptive for families (Heerman, Wilson, & Wilhelm, 2005). Parents of children who are admitted to the PICU often describe this event as the most stressful of their parenting experiences (Noyes, 1999).

The purpose of this qualitative study was to use narrative analysis techniques to analyze illness blogs authored by parents of an infant or child hospitalized in an intensive care unit to identify stressors perceived by the parents and measures used by them to cope with these stressors. In order to carry out this study, a critical review of the literature was conducted. Current literature related to parent's experiences was reviewed to establish current knowledge related to their experiences and potential gaps in knowledge. Social support and coping were reviewed since the conceptual framework and questions of interest are related to how parents perceive the experience of their child's hospitalization and coping strategies utilized. Available research related to the practice of blogging was reviewed to establish the state of current knowledge in this area. The review of literature was then further focused on Internet-based writings by parents about the illness of their child.

## **Review of Research**

### **Parents' Experiences during the Hospitalization of an Infant or Child**

#### **Stressors.**

Researchers have utilized varying methodologies to elicit the experiences of parents with a hospitalized child. The focus of a Danish study by Hall (2005) was experiences of families



when a child or infant was transferred to the critical care unit. She posited that although family-centered care is a focus in pediatric intensive care units, the care at the time of transfer to intensive care is focused on the patient with less regard for the family. For most of the parents, the transfer to the intensive care unit signaled a serious situation and they felt uncertainty and loss of control. Paradoxically, some parents described the transfer of their child back to a less critical area as stressful as they were often unprepared and were afraid that necessary services would not be readily available (Hall, 2005). Psychological distress related to the transfer of their child out of intensive care has been described by other researchers studying pediatric and adult populations (Berube, Fothergill-Bourbonnais, Thomas, & Moreau, 2014; Coyle, 2001; Linton, Grant, & Pelligrini, 2008; Van Waning, Kleiber, & Freyenberger, 2005).

Another qualitative study focused on the experiences of parents of hospitalized children with preexisting disabilities (Graham, Pemstein, & Curley, 2009). Parents were asked to participate in the study during admission if their child was identified as having pre-existing neurodevelopmental disabilities or multisystem conditions requiring complex medical management and coordination of multidisciplinary services, and interviews were conducted during the hospitalization. Some themes identified by the parents as important were consistent with the findings of Hall's study of the general PICU population, such as knowledge of the child's baseline, difference in the caregiving activities parents were allowed to perform, and lack of inclusion of the parents as an expert as new plans are devised. Additional unique categories were identified as well including the need integration of multidisciplinary services and a perception that their child's needs were not consistent with the goals of the acute care model (Graham et al., 2009). The identification of these unique perceptions is significant, considering

that children with chronic illness account for almost half of the admissions to the pediatric intensive care unit (Briassoulis et al., 2004, Dosa, Boeing, & Kantor, 2001).

Two recent studies examined the experiences of mothers and/or parents of children with hypoplastic left heart syndrome. In the mixed-methods study by Cantwell-Bartl and Tibballs (2013), the psychosocial status of parents was evaluated using interviews and psychometric testing after their child had been hospitalized in the PICU. They found that 83% of the parents in their study had post-traumatic stress syndrome, and did not find a significant difference between mothers and fathers. Half of the mothers also reported difficulties with bonding due to being unable to provide care for their infant in the hospital. In the second study, narrative interviews were conducted with 10 mothers of children with congenital heart disease. These mothers identified feeling worried and hopeless while their child was critically ill, and that they were sad when they were unable to provide care to the child. They also expressed feeling insecure when they believed they were in the way of the healthcare providers (Bruce, Lilja, & Sundin, 2014).

The goal of treatment for critically ill children is often aggressive treatment up until the time of death. One study from the pediatric literature focused on anticipatory grieving by parents of hospitalized children (Rini & Loriz, 2007). This exploratory/descriptive study used open-ended interviews to elicit information regarding parents' experiences during hospitalization and leading up to the death of the child. Families in this study identified receiving explanations of treatment plans and preparation for unfolding events as very helpful in navigating their child's death (Rini & Loriz). These findings are consistent with findings in studies of families where the child proceeded to discharge home, and highlights the importance of information to enhance coping, regardless of the outcome.

Colville et al. (2009) completed semi-structured interviews with parents 8 months after their child was hospitalized in the pediatric intensive care unit. Interview prompts included a general recollection of the experience, worst incident they recall, how they coped while the child was hospitalized, and how the hospitalization changed the parents. The researchers identified four emerging themes: vivid memories of the hospitalization, communication with hospital staff, transitions of admission and transfer, and long-term impact of the experience. The parents described their experiences as intensely stressful, and many reported symptoms consistent with post-traumatic stress disorder. They identified both positive and negative effects on their relationships with their child and their family, and some recognized improved coping abilities through this experience (Colville et al., 2009). Similar findings were found by researchers in Lebanon, who also reported communication difficulties with the use of the English language by staff (Majdalani, Doumit, & Rahi, 2014).

A seminal work regarding sources of stress in the neonatal intensive care unit was conducted by Miles, Funk, & Kasper (1992), who identified the alteration in expected parental roles as the most stressful for parents. Additional stressors included sights and sounds of the unit, the infant's behavior and appearance, and unpredictability regarding the infant's illness course. This research led to the development of a scale to measure sources of stress in parents of hospitalized children (Parental Stressor Scale: NICU; Miles, Funk, & Carlson, 1993). Further research focused on types of support parents received from nursing staff, and a tool measuring the parental perception of support received from nursing staff was developed (Nurse-Parent Support Tool; Miles, Brunssen, & Carlson, 1999). Several studies have utilized the PSS: NICU with parents of hospitalized infants and found that parents were most stressed by the appearance of the infant and the disruption of their parental role (e.g. Busse, Strombren, Thorngate, &

Thomas, 2013; Dudek-Shriber, 2004; Seiderman et al., 1997; Shields-Pie & Pinelli, 1997; Sweet & Mannix, 2012).

A group of researchers in India investigated predictors of stress among parents with a child in the PICU. This study was prospective, and parents were assessed for stress using a version of the PSS: NICU adapted for PICU parents. The questionnaire was administered to the parents 48 hours after their child was admitted to the PICU. In this research, there was no difference in parent scores by gender or socioeconomic status. Parents were significantly stressed by the appearance of their child, procedures performed on them, and impairment in their parenting role (Aamir, Mittal, Kaushik, Kashyap, & Kaur, 2013).

Qualitative approaches have been used to examine the experience of being a mother in the neonatal intensive care unit. Fenwick, Barclay, and Schmied (2001) conducted a grounded theory study by interviewing 28 women during the hospitalization of their infant and again 8-12 weeks after the infant's discharge to home. The interviews were very loosely structured with general prompts for the mothers to describe their experience while their infant was hospitalized in the nursery and what helped them to feel like a mother during this time. The researchers identified that interactions with nursing staff had a profound influence on the participants' perceptions of their mothering experience; when the nurses took on an authoritarian role as the expert the mothers felt inadequate and their anxiety increased (Fenwick, Barclay, & Schmied, 2001). The participants were recruited from two neonatal units in the same city in Australia, and visitation policies in those units were not disclosed in the body of this report, and may have affected parental perceptions.

A more recent phenomenological study conducted in Scotland was developed to explore early experiences of parents of a premature infant (Watson, 2010). The theoretical perspective of

this study was critical theory, thus taking the perspective of the parents as potentially being disempowered/disadvantaged. The participants included neonatal nurses in addition to the parents. Recurring themes of crisis, uncertainty, and powerlessness were identified in the narratives of both the parents and the nurses. Watson interpreted the interaction among these themes as creating a lack of social status and detachment in the parents (2010).

Quantitative approaches have also been utilized to evaluate the experience and stresses of parents of a hospitalized child. In a prospective cohort study, Balluffi et al. (2004) measured the prevalence of Acute Stress Disorder (ASD) and Post-Traumatic Stress Disorder (PTSD) symptoms soon after the child's admission to the PICU and again 2 months after discharge. They found ASD symptoms were present in most parents during the child's hospitalization and criteria for a diagnosis of ASD were met in about a third of parents. Criteria for a diagnosis of PTSD were met 2 months after discharge in one-fifth of parents, and the severity of ASD symptoms were predictive of the subsequent diagnosis of PTSD. Additionally, PTSD did not correlate with objective measures of the severity of illness, but did correlate with the parent perception of threat to the child's life. Shaw et al. (2006) studied ASD symptoms in parents with an infant in the NICU, and found that 28% of these parents met the criteria for a diagnosis of ASD, and symptoms of ASD were related to the subjective appraisal of the seriousness of the illness rather than objective characteristics of the infant's condition, such as length of stay, birthweight, or gestational age. Ebrahim, Singh, & Parshuram (2013) described satisfaction, involvement, and presence in a retrospective study conducted one month after the hospitalization of a child in the PICU. These researchers found that in general, the more ICU therapies the child received, the less parents were satisfied with the hospitalization experience. They did not find

any difference in satisfaction between parents who were present and those who were not present during the intensive therapies.

### **Coping.**

A mixed-methods study completed by Uhl, Fisher, Docherty, and Brandon (2013) utilized focus groups to elicit information from parents regarding their experiences during the hospitalization of their child and their perceptions of family-centered care. Parents were asked to give a description of what went well during the hospital stay, what could have been done better, and what would have improved their experience. Three themes were identified from the focus group data: feelings related to the initial shock of the hospitalization, adjustments in the parenting role, and transitioning back to home. In addition, these parents felt that information sharing was an important aspect of their child's hospitalization (Uhl et al.)

Jee et al. (2012) examined parental needs, stressors, and coping mechanisms in parents with a child hospitalized in a pediatric intensive care unit in the United Kingdom. The most frequently occurring stressors identified included fears about the outcome for their child and feelings of helplessness. Coping strategies identified by these researchers were related to trusting that their child would get better, was getting good care, seeking information, and spending time with the child. Seeking and receiving information was also identified as a coping strategy by parents of infants in a neonatal intensive care unit in a study by Smith et al. (2012). Additional findings noted by these researchers included providing care to the infant, getting away from the unit, and support from other parents as well as friends and family members.

The aforementioned studies identify potential and actual sources of stress common in parents of acutely ill hospitalized infants and children, but less research exists in the identification of strategies employed by parents in coping with these stresses. An improved

understanding of the process of parental coping with the hospitalization of a child could enhance the development of interventions to further facilitate coping.

### **Social Support**

Many individuals go through the experience of having a family member or child hospitalized. Everyday life is interrupted, and potential stressors can range from wondering whether their family member will survive to how they will sustain the day-to-day family functions. The Ways of Coping Questionnaire (WCQ) was developed from the TMSC discussed earlier (Lazarus, 1999). The WCQ was utilized in a study by LaMontagne, Hepworth, Salisbury, & Riley (2003) in which parental anxiety levels and ways of coping were measured before and after their children underwent spinal fusion surgery. Emotionally-focused ways of coping were found to be used more often than problem-focused methods both pre- and post-operatively, but the use of problem-focused methods increased after surgery. Seeking social support was reported to be the most frequently used problem focused strategy at both time points. Azar and Solomon (2001) also used the TMSC as a framework for their study of coping strategies of parents with a child recently diagnosed with diabetes mellitus. In their study, the parents were found to utilize both emotion-focused (positive reappraisal) and problem-focused (purposeful problem solving and seeking social support) coping techniques.

Miles and Carter (1983) used the TMSC coupled with a similar coping model by Billings and Moos (1981) to study parental stress and coping in the intensive care setting. Their use of the model led to an ongoing program of research related to stress and coping of the parents of children and infants hospitalized in intensive care units (Miles & Carter, 1985; Miles, Funk, & Carlson, 1993). The TMSC was used to predict the occurrence of post-partum depression by Honey, Morgan, & Bennett (2003). These researchers found postnatal depression scores to be

associated with negative appraisals of anticipated stressors and low perceived social support. Byers & Smyth (1997) utilized the model in a clinical case study to describe patient responses in critical care and to inform the development of specific strategies for reducing stress and maximizing coping in critically ill patients. These studies demonstrate the usefulness of the framework for research as well as direct clinical application.

In a recent study of patients with HIV, the TMSC was the basis for hypothesized relationships between stressors and retention in HIV care over time. This model helps explain how stressors uniquely affect individuals, and the cognitive appraisal of stressors influences the responses and interactions of the patient (Graham, 2015). In another study, researchers used the TMSC in their evaluation of patients who were recently diagnosed with cancer. Their study supports cognitive variables as influencing emotional responses to stress (Hulbert-Williams, Morrison, Wilkinson, & Neal, 2013).

### **Blogging Illness Experiences**

The birth of a premature infant, hospitalization of a family member due to a traumatic event, or having a diagnosis of a potentially fatal disease are a critical event in a person's life. The unexpected nature of such an event leaves patients and family members searching for meaning as they attempt to re-route their lives and change the way they think about the world. One of the ways that patients and families process these new perceptions is through telling stories and attending to the stories of others in similar situations (Frank, 1995). The socially connected nature of our world today via the Internet has introduced a new platform for the sharing of stories. One of the ways this is done is through blogs written by patients and families about their experiences (Heilferty, 2009).



Web logs or blogs have developed over the past fifteen years as a method of online communication for purposes such as sharing political or social viewpoints, as a marketing tool to promote commerce, for informational and educational purposes, and for the sharing of personal stories (Rettberg, 2008). Personal blogs have been found to be the most frequent genre of blogs, and personal bloggers are most often women and youth writing about their everyday lives (Lovheim, 2011).

A sub-genre of the personal blog is the illness blog, where individuals post detailed information regarding their own or a family member's illness. Information offered on these blogs covers a variety of topics, including medical details of illness with personal medical information, impact of the illness on the family and everyday life, requests for informational or substantive support, and personal feelings regarding the illness (Heilferty, 2009; Landro, 2005). Some bloggers use a free illness blog service such as CaringBridge or March of Dimes' Share Your Story to host their blogs and provide a structure for the posting of information. Others use Typepad or Wordpress; these are fee-based hosting platforms for various types of blogs and provide templates for the presentation of the blogger's chosen content. Blogs can also be created and hosted by individuals possessing the Internet savvy to do so. Some sites are publicly available while others are password protected for only selected individuals to be able to access them (Robinson, 2001).

Blogs are similar to a diary or journal as they are a serialized account of events in the life of a blogger that they choose to report. They generally appear in reverse chronological order, with the most recent event or posting appearing first. Unlike other forms of written narratives, the blogger has the option to configure the space of the blog in any way they wish and can use photos, videos, and art as a complement to their written words. They have a beginning and

middle, but may or may not have an ending or reach a conclusion. Blogs also allow for comments by the readers, allowing asynchronous communication between the author and individuals following the blog. This possibility for co-production is a unique quality made possible by technology (Serfaty, 2004). However, blogs are not dependent on interaction, as they are presented as a monologue and do not require interaction to function (Heilferty, 2011). Posts are archived, and may be commented on indefinitely unless the author chooses to close a post to further comments.

Due to the relatively recent development of illness blogs, research in this area is somewhat sparse. Early located studies of online communication examined online support groups and listservs. In an early study, Davison, Pennebaker, & Dickerson (2000) compared patterns of participation in face-to-face and online support groups. They concluded that face-to-face groups were correlated with terminal and costly to treat conditions, while on-line forums were associated with conditions having increased personal consequences such as embarrassment, stigma, and disfigurement. In addition, Internet groups were found to be oriented towards conditions with less available information or overlooked by the medical establishment. The researchers posited that this might demonstrate an advantage of the anonymous format of online interactions (Davison et al., 2000).

In a more recent study, Colineau and Paris (2010) conducted an online survey to collect information regarding how and why patients use health-related social networking sites. Study participants reported that they utilized health-related social networking sites to obtain additional information regarding their health condition beyond that received from their health-care providers. They also sought emotional support through these communities of “others with

similar conditions;” their relationships with their health-care providers were viewed as more clinical and their relationships with online group participants as more empathetic.

Personal web pages are similar to blogs in that they allow for self-presentation structured by the author of the web page, but they may or may not allow for interaction between the author and the readers. Pitts (2004) conducted one of the early studies using illness-related web pages. She performed a content analysis of web pages created by individuals with breast cancer, and concluded that the creation and maintenance of the web pages served several purposes. Authors were both givers and receivers of information through their websites, and peer support networks were created with many individuals posting numerous times on a website and following the progress of the author. Authors also used the websites to as a forum for socio-political discussions of gender and illness, with the website offering a podium that may not have been otherwise available (Pitts, 2004).

In a study of personal web pages authored by adolescents with cancer, Suzuki and Beale (2006) used quantitative content analysis to look for elements of self-presentation, information dissemination, and interpersonal connection. One interesting finding of the study was the variety of elements beyond narrative used for self-presentation, including artwork, photographs, poetry, lists, links, and personal interest pages. The web-page authors utilized informal language and slang indicating the sharing of a group-identity with other teens in similar situations (Suzuki & Beale, 2006).

Using textual analysis to explore personal meaning making and cultural views and responses to SIDS, Finlay and Krueger (2011) examined memorial websites created by parents of infants who died of Sudden Infant Death Syndrome (SIDS). Similar to Suzuki & Beale’s work with adolescents’ online writing, they found that these parents utilized multiple elements in

their online construction of self, including still and moving images, backgrounds and personalized wallpapers. They concluded that the continuing evolution of the websites rather than the presentation of a completed product were consistent with the evolution of the grieving process of the authors as well as an engagement with the larger SIDS community. This represents the dual public and private nature of the creation of memorial websites (Finlay & Krueger, 2011).

Schaffer et al. (2009) evaluated websites created by parents of children who were affected by cancer or genetic diseases. They were interested in how these parents portrayed the illness and available options for treatment as well as how they made decisions related to research participation. Although this research was directed at research and treatment decisions, they found that the websites presented a vivid portrait of the experiences of the families, and exposed their vulnerability in making treatment decisions (Schaffer et al., 2009).

In a recent study in Sweden, bloggers who had a relative with cancer were interviewed by telephone about their experiences with blogging about the family member's illness. These bloggers reported that they benefitted from making connections with others in a similar situation and facilitated their grief process. Some of these bloggers reported negative experiences of public criticism and being misunderstood. The ages of the bloggers ranged from 30-50, but the age of the relative with cancer was not disclosed (Andersson, Gustafsson, Hansson, & Karlsson, 2013).

In a quantitative study cluster analysis was used to determine characteristics of self-identified users of blogs with cancer related content (Kim & Chung, 2007). The researchers identified the majority of blog consumers in this study were highly educated Caucasian females with an average age of 57 years. The participants reported that they used the blogs primarily to

share their stories and emotional support rather than medical information (Kim & Chung, 2007). The relatively small sample size (n=113) hinders generalizability of these results, but they are a starting place for further investigation related to illness blogs.

### **Parents' Internet Writings about Their Child's Illness**

Parents and their experiences in the use of the Internet related to their child's illness have been studied using a variety of methods. This body of literature is relatively small, partially due to the relatively recent emergence of the Internet as an easily accessible form of communication. Historical context plays a role in the synthesis of literature related to computer-mediated communication surrounding illness. The development of these technologies is both recent and ever changing, and this is reflected in the available studies. In the late 1990's and early 2000's, the technology available consisted mostly of asynchronous communication via listservs (emails going out to all members of a group) or bulletin boards (messages posted for viewing by members of a group). Over the decade, the means for creating web pages and blogs has become more accessible to the general population, and incorporates mediums beyond the written word such as pictures and videos to allow a more full range of expression by the author. Existing organizations have developed web-hosting services for individuals experiencing a specific crisis or disease (such as the March of Dimes Share Your Story), and companies have evolved for the specific purpose of providing web hosting such as CaringBridge. These web-hosting services make the use of the Internet for sharing stories of illness broadly accessible to many people.

The studies included in this portion of the review represent a range of different technologies that have been used in research with parents. In the Scharer (2005) study of parents of mentally ill children, Web TV was chosen as the hosting platform for a discussion board. This choice was made in an effort to improve accessibility since this platform could be accessed

from televisions equipped with specific equipment as well as computers with access to the Internet. Although this service advertised statewide coverage, this was found not to be the case when enrolled parents were unable to access the service in certain geographic areas. In addition, the hospital unit from which participants were being recruited was closed for remodeling, and temporary locations were unable to support the simultaneous operation of all the necessary equipment for web access. Parents of six mentally ill children were selected by convenience sampling, and their postings on a discussion board created for the study were tabulated for frequency and topic. The majority of the postings related to illness concerns and group support (Scharer).

In “The Hero’s Story and Autism,” Fleischman (2005) described some of the differences between the more traditional sharing of stories by the parents of children with autism and sharing using new technologies and methods available today. A grounded theory approach was used to appraise 33 websites published by parents of children with autism. Fleischman concluded that the development of websites represented a process of working through grief and identity reconstruction, and that numerous family autism stories have been published as books. He noted that while the book format allows for the sharing of information, it lacks the dynamic quality of discourse in real time that is offered via websites and blogs. He concluded that the interaction between authors and readers serve to shape the future narrative, creating a living, breathing story that reaches out to include new readers in its evolution (Fleischmann).

Modern forms of communication have the ability to construct virtual bridges between individuals who are geographically remote. Gundersen’s (2011) study of the parents of children with rare genetic disorders is an example of this unique aspect of computer-mediated communication. Participants in this study were ten parents of children with rare genetic

disorders who resided throughout Norway and were recruited through a clinic setting. Four of the participants' children had disorders so rare that only a few cases are reported worldwide. Because face-to-face support groups for parents of children affected by rare disorders are unlikely to be available, parents in the study stated that the Internet allowed communication and mutual support among with similarly affected others by erasing the geographic divide between them. This was also identified by Nolan, Camfield, & Camfield (2008) as a positive outcome of the use of web-based communication in their report of interviews with 24 families of children with Dravet Syndrome (a rare, catastrophic form of epilepsy). These authors reported that their study participants did not find participation in support groups for the more common and less severe forms of epilepsy helpful in providing information and support. Connections formed via the Internet with other families with more similar experiences were reported as more supportive and important in decreasing social isolation (Nolan, Camfield, & Camfield, 2008).

The use of computer-mediated communication by parents with sick children was portrayed as having positive outcomes by all of the studies examined here. Only one study reported potential or actual negative outcomes in addition to positive outcomes. In their abstract presentation of interviews with eleven parents of children with cancer who blogged about the experience, Van de Velde et al. (2011) identified that negative comments and criticism added by blog readers was a possible negative outcome of blogging. As a communication medium, blogs are usually open to the public and allow comments by the readers making the author vulnerable to a variety of expressed opinions by individuals with whom they may or may not have a pre-existing relationship.

Van de Velde et al. also identified the intrusion on privacy as a possible negative outcome of blogging. They highlighted the juxtaposition of private information presented in a

public forum and questions regarding the awareness of bloggers of the public nature of this type of communication (Hookway, 2008). This is an area where further research related specifically to blogging about illness is warranted.

Ethical considerations regarding research using information published on the Internet have been discussed by the authors of these studies. One of the factors used in determining appropriate ethical choices is the medium of communication. In her study of perinatal grief online, Capitulo (2004) obtained archived emails from an existing listserv. Since these individuals had participated in the group listserv prior to the involvement of the researcher, and emails constitute a more private form of communication than publically-available blogs or websites, consent was needed prior to the study being done. The researcher accessed the group by subscribing to the list; she then enlisted the owner of the listserv as an observer/researcher who removed identifying data and obtained permission for use from the authors of emails used for the study. The researcher also identified herself to the listserv members as a researcher and posted results of her study on a webpage accessible to the members.

Two studies utilized message boards as their source of data. In Scharer's (2005) study of parents with mentally ill young children, the message board was created for use in the study; consent for use of the message board data was part of the overall study consent. Similarly, the message board in Strohm's (2007) study of the parents of eighteen infants with neonatal encephalopathy enrolled in a larger study was created as part of that research and consent was included with participation in the larger study. When creating a message board or other form of online communication explicitly for the purpose of a study, care should be taken to make explicit to participants that information they post on the message boards may be studied, and their anonymity should be protected. An opt-out option could also be considered so that parents in a



vulnerable situation do not feel compelled have their messages used as data in order to gain access to a potentially life-saving protocol.

Blogs and websites are generally considered to be available for use in research if they are publically accessible and do not require the use of a password or registration for access. This approach was used by Fleischmann (2005) and Schaffer et al. (2009). Heilferty (2011) and Morris (2008) examined blog and website data obtained from private sites (CaringBridge and March of Dimes, respectively) and obtained informal consent from the participants prior to their inclusion in these two studies.

Several common themes were identified in the thirteen studies of parents who wrote on the Internet about their child's illness. These themes are discussed below, and are summarized in Appendix B.

**Initial purpose for Internet writing by parents of an ill child.** Parents in the 2011 study by Van de Velde et al. of eleven parents with a child undergoing treatment for cancer identified the need to quickly communicate and disseminate information to family members as their reason for initiating computer-mediated communication. This was also the reason for website development in a case study by Weingarten (2000), to describe the experience of the family of accident victim with a spinal cord injury. Another reason for initiating Internet writing was to obtain information regarding a recent and unfamiliar diagnosis (Gundersen, 2011; Nolan et al., 2008; Fleischmann, 2005). The studies by Catipulto (2004) and Finlay & Krueger (2011) involved parents of infants who were deceased. These parents cited seeking a way to process grief as their primary initial purpose for Internet writing.

**Discovery of benefits of Internet communication.** As parents continued to communicate and share their stories via the Internet, two studies described their participants

discovering benefits of this form of communication beyond their initial intended outcome (Van de Velde et al., 2011; Weingarten, 2000). These benefits included emotional and social support, information exchange with peers in similar situations, and improved coping with the stress of their child's illness.

**The Internet as a virtual location for tangible memories.** Participants in Finlay and Krueger's study of 20 memorial websites for infants who died of SIDS described their websites as comparable to a real-world gravesite or memorial, with the added benefit of providing increased accessibility by extended family and friends. Authors of 14 blogs hosted on CaringBridge described their use of photographs as creating a virtual repository for memories and milestones (Heilferty, 2011).

**Creation of community with understanding others and reduction of isolation.** Support of others and creation of community have been consistently identified as positive aspects of computer mediated communication. Parents of infants described establishing deep friendships and the sharing of personal information beyond that related to the study (Strohm, 2007). In studies of parents of children with Dravet syndrome as well as that of parents of children with mental illness, a reduction in feelings of isolation was felt to be due to the development of a community with individuals in similar situations (Nolan, Camfield, & Camfield, 2008; Scharer, 2005;).

**Vehicle for sharing and seeking of information.** The sharing of information related to medical diagnoses, coping strategies, and treatment protocols was another theme common among all of the studies. Parents of children with cancer found the ability to seek and find information to be empowering as they made decisions regarding their child's treatment (Schaffer et al., 2009; Van de Velde et al., 2011).

Multiple research approaches were utilized in studies of parents using computer-mediated communication to write about their child's illness. While the overwhelming majority of these studies used qualitative approaches, there was variation among the type of qualitative research approach utilized including ethnography, textual analysis, grounded theory, phenomenology, and case study. Method of analysis was varied, with coding for themes the most frequent method employed. Limitations of these studies included limited reliability due to their narrow focus on a specific disease or patient population and small sample sizes. Since the use of computer-mediated communication related to illness is relatively new, there is not yet standardized terminology among researchers making location of all potentially related studies problematic.

### **Summary**

Hospital admissions of infants and children often come as a surprise to parents and families, and place them in unfamiliar and frightening circumstances. Parents describe the experience of having a hospitalized child as stressful and disruptive to the family. Researchers have identified actual and potential sources of stress, but a gap exists in the literature regarding effective coping mechanisms used by parents in coping with stresses encountered while their child is hospitalized. Online accounts of the experiences of parents with a hospitalized child provide an opportunity for nurses to better understand the experience of these parents and identify stressors and coping behaviors used by families in this situation.

## CHAPTER 3

### **Introduction**

The purpose of this study was to use narrative analysis techniques to analyze illness blogs authored by parents of an infant or child hospitalized in an intensive care unit to identify stressors perceived by the parents and measures used by them to cope with these stressors. In seeking to understand the process of appraisal and coping, four questions were addressed: (a) What stressors do parents report in blogs? (b) What coping strategies are identified? (c) How do the stressors and coping strategies described by parents change over the course of their infant or child's hospitalization? (d) Is there evidence in the blogs to support or challenge the supposition that secondary appraisal leads to problem- and emotion-focused coping strategies? This chapter first describes my research approach, and then details the collection, management, and analysis of these data. Issues of trustworthiness are also discussed.

### **Research Approach**

At a basic level, a narrative is a story that occurs when one or more individuals recount an event or experience. Personal narratives are defined as using language to give logical and temporal order to life events, as well as way of attempting to bring meaning to the events by connecting them to the past, present, and future (Ochs & Capps, 2001). Personal narratives can be formal or informal, recounted after an event with the ending known, or continuing to unfold as new events occur.

The narrative is shaped by the individual conveying the story, but also by the audience consuming the story. Literary philosopher Bakhtin describes the essence of the story developing on the boundary between the listener and the storyteller (1986). The method by which the story is conveyed affects the interaction between teller and listener and thus the shaping of the story. In the telling of a story in conversation the listener may request more information, give signs of approval or disapproval, or interject their own experience, all of which will shape and form the story as a shared experience. The more remote the audience is from the delivery of the story, the less temporal impact they have on the narrative. Even with the reading of a narrative to an audience in a setting not allowing verbal interaction, the non-verbal responses of the audience may influence the way the story is told.

The sociolinguistic work of Labov and Waletzky (1967) is a foundational work in narrative analysis; they defined categories of narrative structure still used in the structural analysis of stories (Riessman, 1993). Their six elements of narrative include the following: abstract (a summary of the story), orientation (the who, what, when, where), complicating action (the plot or point of crisis), evaluation (the narrator's commentary on meaning or emotions), resolution (the outcome of the story), and a coda (ends the story and creates a relationship with the present) (Riessman, 2008).

There is some variation among researchers regarding what constitutes a narrative suitable for analysis (Riessman, 1993). There is a general agreement that the narrative should be a discreet unit with a beginning and some sort of recognizable boundaries, and have a sense of coherence (Labov & Waletzky, 1997; Riessman, 2008; Wells, 2011). Another generally accepted feature of a narrative is a temporal sequence, or chronological ordering of the events through time (Kelly & Howie, 2007; Ochs & Capps, 2001; Patterson, 2008; Riessman, 1993). A

third feature of a narrative is that it is logical to the storyteller, and has some meaning to them (Frank, 1995; Lai, 2010; Langellier, 1989; Ochs & Capps, 1996; Sandelowski, 1991).

Narrative data can be generated in many ways. Often it is obtained through face-to-face interviews, but can also be found in written forms such as diaries, letters, or literary works (Lieblich, Tuval-Mashiach, & Zibler, 1998). Narrative information is increasingly available on the Internet in the form of web pages, weblogs, wikis, bulletin boards, and emails (Eisenlauer & Hoffman, 2007).

Narratives are more than just a report of events that happen to people. The events have meaning to the individuals, and humans have an innate need to share their stories with others. This type of analysis of the individual or family's narrative is a mechanism for illuminating the evaluative point of the story, i.e., what the story means to the storyteller.

**Strengths of narrative analysis applied to illness blogs.** An assumption underlying narrative research is that humans make sense of their experiences by organizing them in a story-like structure (Lieblich et al., 1998). Since illness blogs present a story, the narrative framework is a good fit for the data used in this research, and narrative analysis is one approach for examining how individuals make meaning of events in their lives. This approach allows for both examination of the process and experience of having a child in the hospital and observing the changes occurring over time during the hospitalization. The participants' stories are presented in their own language and in the structure they choose, allowing the researcher to observe the first-hand account of the experiences of individuals (Frank, 2012). Illness blogs are unsolicited narratives regarding the illness of the individual or a family member. This allows for self-selection of the story to be told by the person writing the blog, and so the researcher does not act as an active participant in the story with the potential to shape or change its direction.

**Weaknesses of narrative analysis applied to illness blogs.** Since blogs are unsolicited narratives, there is no opportunity for the researcher to verify or ask for further information or clarification, and he/she must analyze the data “as is.” Through the interpretive process, the researcher imposes meaning on the life experiences of another person. Without thoughtful consideration and awareness, bias on the part of the researcher could lead to a different interpretation than what was intended by the blogger.

Narrative research focuses on the experiences of individuals, and therefore may not be generalizable to other people in similar situations. Background information about the bloggers is limited, and varies among bloggers. There are demographic differences in Americans who use the Internet. In a 2009 survey it was reported that income and education influence internet use with more wealthy and more educated individuals being more likely to use the internet, and people in rural areas less likely to use the internet than those in urban or suburban communities (Pew Research Center, 2014). Considering these tendencies, bloggers may already be in a position of privilege and empowerment and their experiences may not be representative of all parents with a critically ill infant or child.

### **Overview of Research Design**

An ongoing review of the literature was conducted prior to and during this study, focusing on parents’ experiences during the hospitalization of a child and the blogging of illness experiences. Approval for the study was granted by the Office of Human Research Ethics at the University of North Carolina at Chapel Hill, where it was deemed exempt from ongoing contact with the IRB.

**Sample.** Since data were collected from publically available blogs on the internet, no formal recruitment of participants was needed. A purposive sampling strategy was used to

obtain the sample for this study, in that blogs were found using search engines such as Google and Yahoo using terms such as *parent, blog, neonatal intensive care*, and *pediatric intensive care*. Additional blogs were found through links on selected blogs to other similar types of blogs (called blog-rolling). The rationale for using purposive sampling was so that a representative, heterogeneous sample could be obtained (Maxwell, 2012).

Criteria for inclusion in the study were that the blog were written in English by someone who self-identified as a parent whose child or infant was hospitalized, the blog's primary focus was the child's illness, at least five entries were made on the blog, the blog was developed no more than 10 years ago, blog entries contain dates and older posts were archived, and the blog was publically available and did not require a password or approval for access. Children with a diagnosis of cancer were not included as the focus of this study was the experience during the acute hospitalization.

The research plan was for 15-20 blogs or until saturation was reached based on recommendations in Miles & Huberman (1994); 20 blogs were used in this study and saturation was reached. Purposive sampling also included seeking some variety of the child's primary diagnosis. Nineteen children were represented in the 20 blogs. There were fewer children than blogs because there were three sets of twins within the sample (one twin died prior to discharge in two of the three twin births) and four of the blogs were focused on repeated hospitalizations of the same child/children. The hospitalizations occurred between 2005 and 2013, and the age of the children ranged from newborn to age four. The primary diagnoses of the infants and children were prematurity (9 blogs, 12 infants); congenital heart disease (8 blogs, 5 infants/children); and respiratory disorders (3 blogs and children). Two of the bloggers resided in England, and 18 in the United States, with all regions of the U.S. represented. Length of stay of the



infant(s)/child(ren) ranged from 7 to 274 days (mean = 63.4, *SD* = 66.15, median = 43, mode = 17).

Two of the blogs were written by the father of the child, 15 by the mother, and 2 by both the father and mother. One blog was written from the perspective of the infant, and it was not able to be determined which parent was the author. Of the blogs, two are no longer active, seven have occasional entries (at least once/year) and eleven are active with multiple entries per year. Writing styles also varied among the bloggers. All included the date and some sort of title for the entry. One blogger used song titles or phrases from songs for all the entries, with a brief explanation of why that wording was chosen. On average, the bloggers made an entry to their blog approximately every 1.9 days (range = 0.5 to 7.33 days), with a median of 1.2 days between entries. There was variation among blogs in the number of coded data segments per blog entry, so a coded segment-to-entry ratio was also calculated to capture the density of coded data in the blogs. The mean number of coded segments per blog entry was 8.2 (median = 6.5; range = 0.84 to 18.7 coded segments-to-entry). See Appendix C for a comparison table of the bloggers' demographic information.

**Methods for data analysis and synthesis.** Thematic narrative analysis was the approach taken for this study. A combination of thematic narrative analysis as described by Riessman (2008) and applied thematic analysis described by Guest, MacQueen and Namey (2012) allowed for a better understanding of the emerging themes around the theoretical focus, and for finding common thematic elements across different cases. Using the TMS as the framework this study, the experiences of parents with a hospitalized infant or child to identify their appraisal of events, what they identified as stressors and details of the coping processes utilized by them, were examined.

A pilot study was done using five blogs to determine if there was evidence of the identification of stressors and coping within blogs written by the parents of a hospitalized child. The pilot study utilized blog entries during the first 28 days of hospitalization only. Based on the results, there did appear to be sufficient information in the blogs to identify stressors and coping in the data. It was decided that the data should include the entire hospitalization rather than limiting the time period to 28 days. The blogs used in the pilot study were not included in the data analysis described below.

Blogs were transcribed by copying blog text in chronological order into Microsoft Word documents. Photographs and comments from were not included in the transcription. The twenty documents, totaling 591 pages, were saved on a secure laptop computer, and copies of the files were saved on a password protected external drive that was kept in a locked cabinet. Each blog file was assigned a name and the documents were then uploaded into Atlas-ti 7 qualitative analysis software program.

Blogs were read in their entirety to get an overview of the story told in each. In qualitative analysis, themes can be determined inductively from the data and/or deductively by applying a priori themes derived from previous research and theory. For this study, both deductive and inductive methods of theme development were used. Blogs were re-read to identify types of stressors described by the parents. Coping strategies were also evaluated for themes starting with the broad categories of emotion-focused and problem-focused coping identified in the TMS framework. More descriptive sub-categories of emotion-focused and problem-focused coping behaviors were added, and the coding scheme was revised. Each emerging code was added to the code list and defined in the code book, and revision was ongoing. This process included referencing the research questions to ensure that the new codes

were in alignment with the purpose of the research. Blogs were then compared for similarities and differences in the significance of stressors and the methods of coping of different individuals experiencing somewhat similar crises. Within case analysis included changes in coping behaviors over time.

After coding 13 blogs, no new codes were noted. At this time, there were 156 unique codes under the categories of stressors, emotion-focused coping, problem-focused coping, and miscellaneous. The codes were reviewed by five PhD-prepared nursing and social work faculty/researchers with qualitative analysis experience to determine the consistency of the coding as well as that the coding reflected the reality described by the blogger. The codes were discussed with possible schema for sorting the codes into cohesive categories. Codes that were thought to reflect the same content were combined, and any codes with less than five occurrences discussed as to whether they represented unique information or were part of another code. This resulted in the final code list consisting of a total of 16 stressor codes, 26 emotion-focused coping codes, and 23 problem-focused coping codes. The code list was then reviewed with colleagues, and the thirteen blogs were recoded. Using this revised code list, the remaining seven blogs were coded. No new codes were identified during this final coding. Tables of these codes including the frequency of each code are available in Appendices D to F.

Natural divisions occurred within a blog entry when the author or the blog separated the entry into paragraphs, with each discussing a different idea or topic. These paragraphs were the units of analysis and were coded with multiple codes as appropriate.

### **Issues of Trustworthiness**

When considering any research project, the researcher is obligated to consider ways to ensure trustworthiness of the findings, whether the research is quantitative or qualitative in

design. Validity and reliability are well-established benchmarks used to evaluate the trustworthiness of quantitative research, with well-defined procedures accepted within the scientific community.

Where quantitative methodology relies on the conversion of information to numerical data for analysis, data are analyzed in their textual form when using qualitative methods (Carter & Little, 2007). This is a simplistic explanation, as there are epistemological differences as well as methodological ones, but is a starting point for understanding that universal predetermined criteria may not be applicable to both research paradigms (Rolfe, 2006).

This study employed the criteria of qualitative rigor set forth by Lincoln and Guba (1985). Although this set of criteria has been debated as to its applicability across the variety of methods used in non-quantitative research (Emden & Sandelowski, 1999; Porter, 2007; Rolfe, 2006), they are considered foundational and a starting point for the evaluation of interpretivist inquiry (Lincoln, 1995).

**Credibility.** Credibility, as described by Lincoln and Guba (1985) is analogous to internal validity. Credibility is achieved if the data are representative of the experiences of the participant(s); others can recognize the participant's experience through the interpretation of the data (Thomas & Magilvy, 2011). Study results need be an accurate representation of the experience of the participant, and reveal truth outside that of the researcher's own experience (Whittemore, Chase, & Mandle, 2001). Representative excerpts from the blogs have been included in this report in an effort to allow readers the opportunity to evaluate the plausibility of the interpretation of the data.

Peer examination of the codes with spot-checking of coding occurred twice during the analysis process. Consultation with the dissertation committee members was ongoing through

the planning of the research as well as the iterative process of data collection, analysis, and reflection. Ongoing evaluation (as opposed to post hoc) allowed for modification of the sampling to maintain coherence between the research questions and the methodology (Morse, Barrett, Mayan, Olson, & Spiers, 2002).

**Transferability.** Qualitative research methods often involve an in-depth inquiry of a relatively small number of subjects, and selection of the subjects is not usually randomized (Hesse-Biber & Leavy, 2006). The concept of external validity, or the ability to apply findings to the population at large, depends in part on the representative nature of the sample; therefore it is not an appropriate evaluation standard for qualitative research (Lincoln & Guba, 1985). Transferability has been offered as a corresponding evaluation criterion to external validity, and is the extent to which findings of a study are applicable with different subjects or in a different context (Lincoln & Guba, 1985; Thomas & Magilvy, 2011).

Transferability can be enhanced by providing as detailed information as possible regarding the population studied which can then be used by the reader to determine applicability in other situations (Lincoln & Guba, 1985). The degree of transferability is not determined by the researcher but by the reader and depends on similarities between the original setting and participants and the situation of interest for transfer (Hoepfl, 1997). The bloggers are herein described in as much detail as is available on their blogs to allow readers to make comparisons with other populations. The available information included approximate age of the child, child's diagnoses, placement of the child within the family structure, and general geographic location.

In addition, study findings should reflect both typical and atypical elements and fit the data from which they are derived in order to improve transferability (Ryan-Nicholls & Will, 2009). Variations in experiences were explored through purposive sampling in order to enhance

understanding of the experiences of families of a hospitalized child. These variations included a variety of diagnoses, length of time in hospital, and family configurations.

**Dependability and confirmability.** Dependability refers to the ability of readers to follow and evaluate the decisions made by the researcher throughout the research process (Lincoln & Guba, 1985). Another researcher should be able to follow the purpose of the study, how participants were selected, how data were collected, prepared or transcribed for analysis, any theoretical basis for the interpretation of findings, and any techniques used to determine credibility of the data (Thomas & Magilvy, 2011). This audit trail elucidates factors that led the researcher to make decisions and interpretations, and provides a structure for other researchers to repeat the study and assess for similarities/differences in findings (Ryan-Nicholls & Will, 2009).

The concept of confirmability is related to objectivity in the quantitative paradigm (Thomas & Magilvy, 2011). Like dependability, the evaluation of confirmability is dependent on the transparency of the researcher and the research process (Hoepfl, 1997). For confirmability to be evident, the researcher should be reflective during the research process by keeping field notes regarding personal feelings and potential biases (Thomas & Magilvy, 2011). Qualitative research is interpretive in nature, but the researcher needs to critically appraise alternative hypotheses and negative instances to avoid distortion of the data (Whittemore et al., 2001).

As alluded to above, trustworthiness in qualitative analysis can first be improved by transparency regarding decision-making and an explicit audit trail of how the data were handled (Riessman, 1993). Transcripts of the blogs have been archived and samples of the text included in this report (Wells, 2011). Personal memos, coding instructions, data assignments, and other decision related information will also be maintained and available for review (Ryan-Nicholls &

Will, 2009). These will address issues of dependability and confirmability by allowing for the thorough assessment of the methods used in the study (Wells, 2011).

As a source of data for research, blogs can provide a rich and detailed description of the experience of illness for individuals and families. There are some veracity issues inherent in the use of blogs as data – some unique to the format/development of the blogs and others shared with other forms of computer-mediated communication (Heilferty, 2009; Kozinets, 2010). Other issues are similar to those encountered in other forms of narrative and biographical research (Lai, 2010). A discussion of these issues follows.

**Reliability of the information.** A potential question regarding blogs is the truthfulness of their content. There have been elaborately crafted blogs that were actually fictitious accounts of illness, such as that of Kaycee Nicole and described by Jill Walker Rettberg (2008). While it is possible for a fictional site to be developed that does not mean that every site is fraudulent, but it should be acknowledged that fictitious sites are possible. In addition, non-truthful representation is possible in any type of research, no matter how the data are collected. Individuals can easily misrepresent themselves in interviews or on questionnaires (Hookway, 2008).

In this research study, contextual clues such as photos and dates were used to lend credibility to the reliability of the blog (Merrill & West, 2009). All of the blogs authored by the parents of hospitalized children contained pictures of the child alone or with parents or caregivers. Important events such as the first time the mother was allowed to hold the baby or the first feeding were frequently documented on the blog, and the presence of these types of photos lends credence to the authenticity of the blog.

Another way of verifying reliability of information is by looking for coherence; a consistency of characters and their actions which provides a sort of internal validity to the story (Potter, 1996; Rettberg, 2008). In addition, the researcher should consider the issue of fidelity, asking whether or not the story rings true and is it consistent with real life, further demonstrating external validity (Potter, 1996). Approaching the data from a constructivist viewpoint demands that the data must be evaluated in context. As a nurse/advanced practice nurse with many years of experience in the NICU, the investigator has a good understanding of the range of illness trajectories within a variety of diagnoses seen in neonates, and used this expertise to assess the blogs for congruence between the text and the context and individuals it represented. Two additional readers with experience in the neonatal and pediatric population were utilized for additional expert evaluation of a sampling of blogs from the study.

**Authenticity.** The possibility that the author of the blog is presenting an ideal or other iteration of self rather than the authentic self is more likely than a fraudulent site. This is a consideration with any form of narrative research (Paley & Eva, 2005; Polkinghorne, 2007). There is concern that presenting one's self using computer-mediated communication may be less reliable than face-to-face interaction, somewhat related to stories of false presentation on the Internet such as that described above (Hookway, 2008). In a study of comparing online and offline behavior of men and women in Internet chat rooms, Whitty (2002, 2004) found less falsification of identity than in early studies in Internet use conducted in the late 1990's by herself and other researchers. Men were found to lie more about education, occupation, and income, consistent with offline dating behavior (2004). In a 2009 study by Subrahmanyam et al., 195 blogs written by self-identified adolescent females were analyzed related to presentation of self, and a sample of entries (three per blog) were coded for format, content, tone and style. The



researchers concluded that the purpose of these blogs appeared to be to create a narrative about people and events in the adolescents' lives and was consistent with developmental tasks of adolescence. This suggested a psychological connection between the bloggers' online and offline contexts (Subrahmanyam, Garcia, Harsono, Li, & Lipana, 2009).

Illness blogs are a form of a narrative as they are a story that includes temporal ordering and an attempt to make meaning of those events (Heilferty, 2009; Sandelowski, 1991). Within narrative research, it is understood that the story offered is not necessarily a factual account of what happened, but a description of the storyteller's perception of what happened (Riessman, 1993; Sandelowski, 1991; Wells, 2011); the question is not one of absolute truth but of the significance the events held for the narrator. Consistency within the projected persona of the blogger was evaluated with the understanding that the individual or family unit was experiencing a time of change (Frank, 2010); within the blogs used for this study, the persona of the bloggers remained consistent throughout the child's hospitalization.

**Textuality and disembodiment.** A related issue to authenticity is that of textuality and disembodiment, problems identified in the computer-mediated communication literature (Androutsopoulos, 2011; Kozinets, 2010). Data obtained from the Internet are heavily textual, and not immediately associated with a particular person as is the case in face-to-face interaction. With textual data, visual cues of body language, auditory cues such as change in tone and pauses, and cultural context cues are missing. This can lead to a sense of disembodiment; a feeling that online interactions and information from online sources are not real (Kozinets, 2010). All of the blogs studied here contained photographs consistent with the stories described by the bloggers.

**Representativeness of records.** It would be impossible to locate all of the blogs of a specific type or pertaining to a particular disease or problem, since they are hosted and linked in

a variety of ways. Therefore probability sampling would be impossible (Li & Walejko, 2008). For this study, purposive sampling of blogs written by parents of a hospitalized infant or child and written in English was conducted using Internet searches and blog-rolling.

There is a problem of selective survival related to blog data: what survives may not be all of what was published. Although blog content is archived, blogs can and do disappear. All blogs used in this study were downloaded and saved prior to analysis (Herring, 2010). There is no assurance of the continuation of a blog; it can be abandoned at any time. If the research included specific time points or developmental stages, these blogs would be lost to sampling (Li & Walejko, 2008; Rettberg, 2008). The text of the blogs was loaded into Atlas-ti7 for archiving so access to the blog content was maintained through the completion of the research project.

### **Summary**

Narratives are more than just a report of events that happen to people. The events have meaning to the individuals, and humans have an innate need to share their stories with others. This type of analysis of the form of the narrative is a mechanism for illuminating the evaluative point of the story – what the story means to the storyteller. The purpose of this study was to use narrative analysis techniques to analyze illness blogs authored by parents of an infant or child hospitalized in an intensive care unit to identify stressors perceived by the parents and measures used by them to cope with these stressors. Also examined were how those stressors and coping strategies changed over the course of the hospitalization.

Threats to the validity of this study included issues of credibility, transferability, reliability of the information, textuality and disembodiment, authenticity, and representativeness of the records. These issues were addressed by the careful examination of the blogs included in the study for a plausible story supported by the stable voice over time of the narrator and visual

confirmation of the family's experiences through photographs included on the blogs. Issues of dependability and confirmability were addressed by archiving the full content of all blogs along with coding and memos regarding the analysis process.

## CHAPTER 4

Using narrative analysis, this study was designed to examine the illness-related blogs written by parents of children hospitalized in an intensive care unit, specifically to identify any stressors expressed by the parents and, when available, methods used to cope with the stressors. Blogs written by parents during their child's hospitalization provided a rich description of how they appraised and coped with this stressful situation. In seeking to understand the process of appraisal and coping, four questions were addressed: (a) What stressors do parents report in blogs? (b) What coping strategies are identified? (c) How do the stressors and coping strategies described by parents change over the course of their infant or child's hospitalization? (d) Is there evidence in the blogs to support or challenge the supposition that secondary appraisal leads to problem- and emotion-focused coping strategies? Qualitative research methods allowed the researcher to examine these questions in order to better understand patients, families, and the social context of health care.

For this report of research findings, bloggers will be identified with a letter for the type of unit their child was hospitalized in (N = Neonatal ICU, P = Pediatric ICU, and C = Cardio-surgical ICU) and a digit assigned to their blog document for this research (1-20). Within direct quotes, I used brackets to replace the names of the children, parents, siblings, and hospitals to maintain anonymity. The language, presentation, and punctuation of the bloggers have been preserved, and spelling and/or grammar deviations are presented as they were in the original blogs.

## **Research Question 1: Stressors Reported by Parents**

In examining data from the blogs using the TMSC as a theoretical framework, it was found that parents identified many stressors related to the hospitalization of their child. Identification of these stressors was both explicit (blogger stated that something specific was causing them stress or worry) and implicit (stress was implied when the blogger wrote that they felt relieved or better after something had ended). Initially, sixty different types of stressor were identified and each was given a name (code). The quotations associated with these codes were compared and defined. Some codes were merged and all codes were examined for commonalities. From further analysis, the remaining codes were grouped into six major categories (themes). These identified themes for types of stressors are child-related, hospital-related, information, parenting, and self-related.

**Child-related.** Bloggers identified several types of stressors that had to do with the child's appearance, behavior, and comfort. These stressors were child-centric and discussed by the blogger in terms of the child rather than the diagnosis or medical information related to the child (those stressors are covered in another category). Child-related stressors were identified in all twenty blogs.

***Child's appearance.*** These stressors were related to how the child looked to the blogger. They included physical attributes as well as extraneous items such as medical equipment. N14 is the mother of a premature infant and gives an example of this: "The first time I was her I couldn't believe how small she was, and all the tubes and everything attached to her of course I broke down again." The previous quote also demonstrates an element of surprise sometimes expressed when the child did not appear as the blogger expected.

Bloggers often provided a count of the number of tubes or wires involved as they painted a picture for the reader, as with C12 whose child had open-heart surgery:

She has 2 chest tubes that are draining, nicely, 2 pacing wires in case her heart needs paced, 4 IV's, and IJ in her jugular, a central line on her left hand (poor baby can't suck her thumb with her boarded hand) a peripheral line in her foot, a femoral line in her groin and a urine cath.

This category also included the global appearance to the parent such as when there were many people at the bedside. The distinguishing factor of this sub-category is that the stressor is related to what the blogger sees rather than what the child does. Fifteen out of twenty bloggers identified the appearance of the child as a stressor within their writing.

***Child's behavior.*** Stressors in this category relate to the behavior of the child and included physical demonstrations of distress like crying and kicking. The mother of a child in the PICU (P7) identified seeing these behaviors as stressful:

In all honesty, it's the most upset she's ever been since she was an infant and was convinced that all adults were idiots. (That has not really changed). She was distraught and scared and angry and uncomfortable and very, very tired. She was nearly hysterical and it was an awful.

Unresponsiveness and non-recognition of the parent were also included in this category of stressors, demonstrated in this quote from another parent of a child in the PICU (P8): "She just lies there...I would give anything right now to be able to just see her look at me and smile." This code was identified in fourteen blogs in this study.

***Child's discomfort.*** Fourteen of the blogs also contained references to how the discomfort of the child was stressful to the blogger. Included were discomfort caused as a result of treatment or procedures as well as difficulty breathing, hunger, or other noxious sensations.

The blogger often used the words “comfort,” “discomfort,” or “uncomfortable” and related that to their own stress, as in another posting from P8:

About 15 minutes post-extubation, I was holding on to {} and just apologizing to her. I felt so horrible for her. She was struggling so hard. It broke my heart. I think watching her struggle to breathe, struggle when agitated and just overall uncomfortableness is making me stressed out and completely sad.

In the blog written from the perspective of the child (a premature infant in the NICU, N10), the blogger wrote the following: “Because of the ventilator I now have to lie on my back which isn’t as comfortable and makes me fidget a bit more.” In this quote, the stress of the blogger is assumed since they chose to write about the child’s discomfort. This quote could have also been coded as the *child behavior* stressor since fidgeting was mentioned. Since both codes were within the larger theme of *child-related stressors*, only one of the codes was used.

**Hospital-related.** The next category of stressors identified by the bloggers was related to hospital issues. This theme included four sub-categories: errors, sensory, staff, and system. All of the bloggers described stressors from at least one of these sub-categories. These stressors were related to the hospital as an environment, the interactions with hospital personnel, and error that occurred within the hospital.

**Sensory.** Sixteen bloggers identified the hospital sights and sounds as being stressful. The sounds of the alarms, other children crying, and the general noise of the nursing units were described. One parent of a premature infant (N6) gave this description of the noise in the unit:

The NICU is very noisy. There are alarms going off all the time. Some to let you know that the babies’ monitors have come unattached. Some to let you know they have too little or too much oxygen in their bloodstream And the worst of all, the brady monitors, which tell you that they’ve stopped breathing and their heart rate is going down below 80. This monitor’s alarm is 3 very loud, very short beeps. You can hear them all over the NICU. The sound is so pervasive that I hear them in the house sometime. (Ghost bradys). A police car with its light and siren on came up behind us the other day and I thought it was a brady alarm.

Visual stressors were also identified, as with the mother of a premature infant (N9) who said, “I didn’t expect to see the baby underneath a Bili light...he was an odd red color due to the blood transfusion they were giving him. Beside his isolette there was a Christmas tree of medicine pumps.” Another blogger described the stressor as both auditory and visual, stating “Alarms, buzzers, and busyness was what I saw when I walked in” (N14).

**Error.** Ten separate actual or perceived errors were reported on six of the blogs.

Although not occurring on a majority of the blogs, these incidents are worthy of discussion and inclusion as stressful events for parents. Two errors included an umbilical line being accidentally pulled out and the wrong umbilical line removed after being replaced. Both of these errors occurred on the same patient, and the blogger (N4) wrote the following:

So we were ok with all of this on Saturday morning and afternoon – but then – last night at about 11:00, we got another call from the NICU. They were going to remove one of the umbilical lines because it was no longer needed, and they accidently removed the wrong one (once again, the one giving him the medicine to keep the patent ductus open)... So right now the umbilical lines have both been removed but he now has three IVs – one in his foot, one in his hand, and one in his head (this is stressing me out just writing about it!)

Other types of errors that occurred included the inadvertent removal of endotracheal tubes and feedings tubes, incorrect supplements added to feedings, burns on a child’s chest from defibrillation, and being given incorrect test results and/or diagnoses. After her child’s ventilator tubing became disconnected and there was a delay in realizing this as the cause in a drop in the child’s heart rate and oxygen saturation, N9 said

This was the third time that is has happened since he has been at {} Hospital. I couldn’t help crying from frustration. {} has so much to deal with already! How many times can my heart break for him? What else will he have to go through? What damage has been done by human hands?

Another type of error reported by 11 of the 20 bloggers (15 separate incidents) was a delay in treatment. These occurred for a variety of reasons, including specialty physicians not



available, beds not available in specialty units, inability to obtain blood samples, no appropriate personnel available to read tests that were completed, and unit personnel too busy to complete orders. One mother of a premature infant stated “Oh, the scan that he was supposed to have yesterday didn’t happen until late this afternoon which means that we have no results Trying not to be nasty about that one” (N15).

**Staff.** Another hospital-related stressor involves the health care providers in the units caring for the patients, and was reported in 13 of the blogs. These types of stressors include *direct conflict with staff, being unfamiliar with staff members, conflicting medical opinions, and questioning treatment.* *Conflict with staff* was reported in seven of the blogs. Confrontation was not necessarily overt, but the blogger expressed stress related to interaction with the staff or a feeling that the staff were not listening to them. A mother with a child in PICU (P8) said “I’m frustrated, incredibly frustrated. I shared my frustrations with her attending (our third one in the PICU, and the first one who I feels actually listens to me).” Although her interaction with the current attending isn’t necessarily stressful, her perceived lack of being heard up to this point has been stressful. A mother of a premature infant also identified not being heard as being stressful, stating

The nurse spoke to {the father} only – as she had when I had visited the baby earlier in the day with my parents. I was becoming increasingly frustrated. Did they feel like I didn’t need to know or couldn’t handle what was going on with the baby? (N9)

Four bloggers described having *unfamiliar staff* take care of their child as stressful. This code refers to trusted staff not being available and/or staff they didn’t know caring for their child, although they expressed understanding that it isn’t realistic for their favorite or familiar nurses to be available every day.

*Conflicting medical opinions* expressed by different health care providers was another source of stress for six bloggers. These differences were described as occurring between the doctors and nurses, doctors and doctors, and nurses and nurses. Some of these incidents were related to the changing of attending physicians that occurs on a regular basis in most teaching hospitals, with the oncoming physician changing the plan of treatment that was in place with the former attending. As N9 stated:

Dr. {} comes back tomorrow and I'm sure he will have plenty of changes to make It's hard when another doctor takes his place for a week or two because their plan-of-action may not be what he had in mind. Then, once Dr. {} gets things going his way, another doctor comes on and changes it around again. I'm surprised they get anything accomplished!

When writing about their child's lack of progress, C13 wrote "Unfortunately, if there has been any improvement, it is minor (and it depends on which of his 284 doctors and 153 nurses you ask)." From the phrasing of this statement, it is clear that hearing these different opinions was stressful for the parent.

A similar type of stress related to staff occurred when the parents have a different opinion of the best treatment option than the care providers, which was reported by nine bloggers. The parents formed their own opinions based on several factors, e.g., prior experiences, experiences of others (observed in the unit their child is in as well as through interaction with other bloggers), and information found through their own research (reading and online). C13 eloquently describes their feelings regarding the balance of information and opinion:

Why is it that one day dropping pressures and beeping alarms are a big problem, and the next day those same pressure readings and beeping alarms are a "wait and see" indicator? I trust the docs, but I want so desperately to see signs of improvement and tend to latch onto anything that will tell me he's getting better. Sigh.

**System.** The fourth sub-category of hospital stressors is related to system issues. These include *unit rules, changes in location, spatial issues, and things not as expected/miscellaneous*

*issues*. All 20 bloggers reported stressors related to hospital-system issues. Unit rules and change of location stress were each reported by 13 bloggers. One type of rule that caused stress pertained to unit visitation limits or hospital-wide limits on visitation due to community illnesses. Although visitation in NICUs and PICUs is generally more liberal than other areas of the hospital in the amount of time that families and their supporters can spend at the bedside, the number of visitors is often limited to two per bedside at a time due to limited size/space available around the bed. Visitation by siblings is often restricted and can only occur after appropriate vaccination records and been reviewed and when there are no signs of illness in the sibling. Also, during times when there is an increased number of influenza and respiratory syncytial virus, visitation by children under the age of twelve may be restricted. This was stressful to parents who want their family to be together as a unit. Visitation may also be restricted during times when shift change is occurring and/or when the unit is admitting a new patient due to space limitations and in an effort to maintain confidentiality for patients. This code was applied to data where the blogger specifically mentioned the rules causing stress rather than referring to separation from the infant. An example of this is found in the blog by N9, where the blogger states, “I told the nurse that I was going to go to my mom’s sleep-room. She gave me a very stern look because people aren’t supposed to share a room – she was adamant that we not break the rule.”

Rules limiting holding or touching their child are also stressful to parents. Often these rules are due to the condition of their child, but some restrictions are in place because of specific equipment or the time and effort involved with moving the child into position to be held. The stress caused by these restrictions was evident when the mother of a preterm infant (N1) wrote “while he is on the nitric we can’t hold him, but I dare any nurse to tell me I can’t touch him.”

Changes of the location of the child can occur for several reasons. Within a facility, patients can be moved to different units because of changes in their condition and the need for an increased or decreased level of care. Patients can also be moved when dictated by staffing or space concerns. When a specialty not available at one hospital is needed, the patient may be transferred to another facility that has the needed specialty. Large tertiary centers with multiple specialists may transfer patients to smaller facilities once testing or procedures are completed, especially if their beds are in high demand. These moves can be stressful for parents even when the move is for a positive reason like an improvement in the patient's condition, as the family may have bonded with familiar staff and has developed a specific routine based on that unit. When an infant in need of surgery (N3) was transferred to a facility with pediatric surgeons, the mother wrote, "We had our routine. And then our new "normal" got all jostled around with moving to {} Hospital."

Stress related to spatial issues was found in 12 blogs. This sub-category included when no beds were available for admission or in an appropriate specialty unit. P8 wrote "sitting in the main waiting area at {} Hospital with {}, who has a nasal cannula, pulse ox, and 2 IVs with over 50 or so sick kids because there are no rooms available. I'm one pissed off mommy!"

This sub-category also included lack of space for parents as well as patients. Some hospitals have sleep rooms available in the hospital; others have a nearby facility (for example, Ronald McDonald House) where parents can stay for a nominal fee. While these are a service to families, they provide a limited number of rooms that is often exceeded by the number of families needing them. They must often be requested on a daily basis with no assurance that you will be able to stay there night to night. Another mother of a child undergoing surgery (P5) wrote: "We were not able to get a bed in the Ronald McDonald House so we'll be sleeping in

recliners here in his room and the PICU waiting room tonight. Looks like it's gonna be a long night."

Although unavoidable at times, issues of space occur within units as well. N14 wrote:

My first visit with {} didn't go well, there were not any rocking chairs available, so I had to hold her in an office chair (not very comfortable). She didn't wake up enough to nurse. Then when I went to the pump room, they had it all torn apart, as they are going to put a new baby in there (so I had to pump sitting in a room in disarray also sitting in an office chair.

Two bloggers identified stress related to their child being moved to a new location or taken for a procedure without their knowledge and the distress they experienced when they went to the former bed space and their child wasn't there. P8 said "I came down around 8 am, and {}'s room was completely empty and being scrubbed down by the cleaning staff. My heart skipped quite a few beats."

**Information.** Coding of the blogs for themes yielded a large number of data that were centered on the concept of information as being a stressor. These data were further analyzed and sub-categorized into 4 main groups: *knowing*, *not expected*, *not knowing*, and *waiting*. All of the blogs contained data coded as information-related.

**Knowing.** These are things the parent knows about the condition of the child and that he/she finds stressful. Something being known and causing stress is dependent on the parent understanding that what they are seeing or being told is not positive. For example, if a parent sees the heart rate or saturation decreasing on the monitor, it is stressful if the parent knows that this is a bad clinical sign and indicates a worsening condition of the child or potential problems. If they had no understanding of the negative impact of desaturation or bradycardia, it would likely not be a stressor to them. Nineteen of the bloggers identified stressors from this category.

The current clinical condition of the child was frequently identified as a source of stress for the parent and was applied to 158 data segments. The mother of a premature infant (N1) gave a simple description of her observations, “Tuesday & Wednesday were very stressful days. {}’s saturations were hanging out in the high 70s to mid 80s with his resting heart rate around 140. Much higher than his norm during the month of December.” Another mother’s description of knowledge as a stressor indicated a detailed understanding of the complexity of her child’s condition:

Without diuretics, {} would retain fluid. Some of that fluid would stay in the lungs and cause them to have to work harder. The nurse practitioner tried to switch from Lasix 2 times a day, to once a day – but {}’s urine output decreased dramatically. Now they are trying to give another diuretic that isn’t as strong as Lasix in place of it once a day. It’s all a balancing act. (N9)

The knowledge of potential complications was another source of stress identified in fifteen of the blogs. Although it is important to educate families and patients about potential complications related to their condition and treatment, it should be noted that this knowledge is in and of itself stressful. A mother (N16) stated:

{} spent 16 hours on CPAP but unfortunately needed to be reintubated this morning. The level of oxygen that she was requiring with CPAP was just too high, which could potentially cause severe eye damage. While going back on the ventilator was disappointing, we knew it was a possibility.

Her stress stemmed not only from the current treatment choice (CPAP or ventilator) but also from the potential damage that could be caused by excessive oxygen (eye damage). Another blogger (N17) voiced their concern regarding potential complications:

{} was in isolation due to an E-coli bug they found on his skin swab. And more devastatingly, they found a large blood clot in his heart, it was flappy around in the right atrium, this was a huge concern and for the first 48 hours, {} was at high risk of suffering a stroke, brain damage or at worst fatality.

A similar type of stress related to knowing occurred when parents were asked to make a decision regarding their child. Part of this process involves risks and benefits of treatment as well as non-treatment, as this knowledge is inherently stressful, especially when the responsibility for the outcome is placed on the parents. Eleven bloggers identified these types of situations, which included signing consent forms for surgery. The mother of a premature stated:

So, he has been requiring a lot of oxygen the past day or 2, too much of that over time causes damage to the eyes. He could get steroids to help the lungs, however those can cause neurological side effects that we will not know about until he's older. Every decision we make is like this...If you don't do anything, there are problems – and if you treat it, there are more problems. They are impossible decisions. (N3)

On the 274<sup>th</sup> day of hospitalization, one mother's posting regarding decision points illustrated the magnitude of decisions parents are asked to make regarding their child:

I am going to make this very brief. One side of {}'s heart is not working and the other half is working poorly. They have done all they can do. I will update more but as of right now he is not going to make it through the night. We are taking him off life support tonight because he cannot recover from this. (N1)

Twelve of the bloggers specifically targeted the moment they came to realize their child's situation as particularly stressful. This quote from the father of a patient with heart disease illustrates this point:

I don't think he saw anything from the cath results that surprised him, and it wasn't that he told us things were worse than they thought – but as he explained the situation, the realization of how complex this condition really is started to hit {the mother} and me, and we started thinking that there could, possibly, come a point where they had done everything they could and would not be able to go any further. (N4)

The mother of a child in PICU with the diagnosis of a chronic illness reflected on her thoughts regarding realizing their situation:

I am just really, really sad now...It is not just the physical trach itself that makes me sad...it is mostly that this is slap-in-the-face "I told you so" progression of her Gaucher's disease. It is that invisible hump that once we climb over, we are in a whole new world – the world of a truly medically fragile child, not a child with just some special needs. (P8)

*Not expected.* Another category within the broader theme of information are stressors related to the unexpected. Included in this category are *new diagnoses, not responding* to or *adverse effects* of treatment, *worsening condition, prolonged hospitalization* and the *always-changing* nature of critical illness. As a group, sub-categories of within the not-expected group were coded the most of any subcategory with 318 instances noted and they were noted in all of the blogs.

*New diagnoses* are one of the types of information in the not-expected category. With the new diagnoses comes a new set of information including treatment, prognosis, outcomes and new potential problems. One mother said the following about a new diagnosis:

{ }’s newborn screening came back from the state...and blood work shows that she may have PKU. It is the first time I have ever heard of it, but basically her body may not have the enzyme required to process a certain amino acid in proteins. If not treated, it can be bad news Treatment basically consists of a VERY strict low or no protein diet for the rest of her life. There is more to it, but I need to read/talk to doctor more. (N2)

Here are the words of another blogger upon learning of a new diagnosis:

The not so good news is that just as we were starting to breathe a sigh of relief that his sats were finally showing an improvement (and my mom and I were about to leave for the day), he started having episodes of SVT, or Supraventricular Tachycardia. (N18)

Another form of unexpected information causing stress occurs when a child suffers *adverse effects* of treatment or is *not responding* to treatment. When a treatment is started, the assumption is that the treatment will work and adverse effects will be minimal, but that is not always the case. The mother of a child in PICU (P8) described her child’s lack of response to treatment, saying “This morning was a rough one for me...their ‘plan of care’ for { }’s sedation wean for an extubation trial Thursday morning that was created a couple of days ago seemed to be not working.” A common occurrence with intravenous lines is infiltration, but the following quote demonstrates that even though it is routine for nurses, this adverse effect of treatment is



stressful for parents: “She had another go-round of getting poked, again, for a new IV. The only one they left in was not working anymore, leaky, and a swollen leg because of it. Ugh!” (C12)

Not surprisingly, the worsening condition of a child is stressful for a parent. Following are 2 quotes in which the parent identifies that they had an idea of how things would be and the situation not going as expected is causing stress for them.

But after PICU, {} didn't take any steps forward at all. She couldn't keep her oxygen saturation levels up without a good deal of extra oxygen. By Tuesday, {the father} and I were getting more concerned. This isn't our first trip to the pediatrics party and {}'s recovery did not seem to be playing out like we expected. (P7)

When I left the hospital I was hopeful and feeling good about the day's progress. I called the NICU a few hours later to see how {} was doing on the CPAP and all was well. Unfortunately, when {the father} returned in the evening, {} needed to be re-intubated. Her carbon dioxide levels were slowly rising and she was not doing well on the CPAP... Hearing this was concerning and I wondered if {} was getting worse. (N16)

Hospitalization that lasts longer than the parents anticipated is another variation of the unexpected causing stress. Health care providers are routinely questioned about the expected length of a hospital stay. For example when a child goes in for a planned procedure as with staged heart repair, they are given an idea of how long the child will be hospitalized. When these expectations are exceeded, the parents experience stress. In the words of one mother:

Today is a bit of a hard day for all of us. When we had originally planned our trip, we had been told to expect to be here about 2 weeks. Today is the end of that 2 weeks....We knew there could be complications that could keep us here longer than 2 weeks, but we always assumed those were things that happened to other people. (C13)

***Not knowing.*** In addition to what is known, the unknown can also be a source of stress for parents. Bloggers frequently reported anticipating bad news and the fear of a bad outcome as stressful. One parent (C13) noted: “We were almost able to celebrate this big milestone, but I

think from now on we'll always take good news with a bit of 'Okay, where's the hitch?' mixed in." Another mother's words are representative of thoughts expressed by other bloggers:

To be honest I am scared to call and check on her or even walk to her bed sometimes because she is doing so well and I am afraid of bad news. You always hear the whole 1 step forward, 2 steps back thing in the NICU. The last couple of weeks she has done really great and I love getting good news, but I let myself worry about something setting her back. (P2)

*Not knowing* also takes a more general form when the condition of the child, complications, or response to treatment is unable to be explained by the health care providers. Seventeen bloggers described the unknown as causing stress. The words of this mother describe her frustration with *not knowing*:

So, all to say things have gotten incredibly frustrating. {} is in the best hands right now (both the doctor's and God's, but no one can figure out what's going on with him so that they can fix it and actually get us out of the hospital. SOOOOOOOOOO frustrating. (N18)

**Waiting.** The final group of sub-categories related to information has to do with waiting. Waiting in the hospital takes multiple forms --- waiting for test results, waiting during surgery or procedures, waiting for an upcoming milestone or goal towards progress to be met, and waiting for news. Nineteen of twenty bloggers described a time when waiting was stressful for them while their child was in the hospital. After her son was transferred to a larger medical center for evaluation for possible surgery, the mother reflected on waiting for pending news in the following way:

It's hard to constantly wonder if you are about to be in a stressful situation or if things will stay calm. Everything in your mind and emotions is heightened during that time...it's hard to describe, and basically it's stress but none like I've ever experienced before! (N3)

Waiting was a common experience for many parents. On the 95<sup>th</sup> day of a premature infant's hospitalization, the mother said this about waiting: "Sounds like we are in for another spell of

waiting. Waiting for {} to take the bottle. Waiting for more growth. Waiting for eyes and ears to develop.” (N9) Another mother described her experience with waiting:

{} has been doing well after her brief return to CPAP. She has been off since 9:00am yesterday and has been doing fine. The attending physician indicated that he likes to keep babies for observation for at least 48 hours after “events” such as the one {} had. So we are back to watching, waiting, and wondering when she will come home. (N16)

**Parenting.** The bloggers in this study reported stress as a result of alterations in their role as a parent. Stressors related to this theme were noted in all of the blogs studied. Sub-categories were identified, and include role alteration, home concerns, changes in level of responsibility, and empathy for other families.

**Role alteration.** Role alteration occurs when the parent is unable to carry out activities they perceive to be a part of the parenting role. One barrier to parenting identified is separation from the child, and was reported by thirteen of the bloggers to be a source of stress. The mother of a premature infant (N2) described the pain of being separated in this way: “{} is starting to be a lot more alert when we come to see her...opens her eyes wide and looks around and listens to us talk to her. It’s getting harder and harder to leave her at the hospital because of this.” This separation was magnified for this parent of premature twins (N6); she stated “{twin A} came home on Wednesday and it was a hell worse than you can imagine leaving {twin B} there.” Another mother was separated because of her own illness. After not being able to visit her premature infant for a week, N14 wrote “how can it be possible that I am a new mother and have not been able to see my own daughter for a whole week. It’s just killing me emotionally.”

Another form of role alteration occurs when the parent is able to be present with the child but unable to hold or touch him or her. This is usually due to the condition of the child, since even when the parents express an understanding of the reasoning behind the restriction it is still

stressful for them. Eleven blogger identified this as a stressor. N6 echoed the sentiment of several bloggers when she stated

So I really can't interact with her yet because it hurts her breathing, her oxygen intake, and her heart rate. That sort of sucks, in case you were wondering. I know (hope, believe) that I will be able to hold and bond and parent my children, but at this point, I feel like a visitor to my own children's bedsides.

The mother of an infant after heart surgery (N18) implied the stress she experienced at not being able to hold her infant by stating "they're planning to close his chest tomorrow...which puts us one step closer to holding him again! YAY!!!!!"

Related to this is the stress parents experienced as they mourned the loss of the parenting experience they had expected to have or had prior to the hospitalization of their child. N3 describes her experience in this way:

Getting to hold him was not "holding" like you dream about after having your baby...we had to be very careful, still, and exact with where we picked him up! Basically I put one hand under his bottom and hips and the other hand under his head and neck and just lifted him for a few seconds off the bed, then put him back down and they weigh him.

Another mother with a child who had been hospitalized for 3 months (N16) reflected on how her parenting experience was changed, stating:

Sometimes, although only briefly, I forget how young she was when she was born. And although she is 37 weeks now, she is nowhere near being in the same position as babies who are born at 37 weeks. Had she been born today, we probably would never had to worry about desats, bradys or apnea episodes.

Parents also wrote about mourning the loss of a "normal child, and the stress this caused them were evident in their words. P8, the mother of a child hospitalized with respiratory failure and now diagnosed with a chronic illness said it this way "I actually had to look on my computer just now to see what day it was. I can't believe it is already Friday! Sunday, {} was playing with her toys, cuddling, and just being {}. Today, well, you know...." A parent of a premature infant

(N3) said “And so, we may have yet another thing to mourn. Having a healthy baby...and a healthy child.”

Parents described stress related to feelings of helplessness in nine of the twenty blogs studied. They were frustrated as they recognized that the child had needs such as hunger or difficulty breathing and yet they were unable to help them as they felt a parent should. N14 succinctly described these feelings, stating “Going to the NICU is so difficult as there isn’t anything we can do We go in, stare at her, cry for her, whisper to her, that’s about it.”

***Home concerns.*** Having a child in the hospital causes disruption in the usual routines of families, and this is a source of stress. Ten bloggers described several different types of home issues, from seemingly mundane of a sick dog and can’t find time to take him to the veterinarian to a planned move out of state requiring packing up of belongings and finding a new place to live (this occurred with two of the bloggers). The parent of a child in PICU wrote

The day {} was life flighted to {} Hospital, we were told that he would likely be here for 7-10 days. Today was day 13...In the irony of life, there was more scheduled to happen in the past two weeks of our lives than any other two week period in the entire year...without me there to help or direct, all of our things were packed up and hauled to our new house today. (P20)

Financial concerns can also cause stress for families, and were mentioned by four bloggers. Employment concerns were noted as one father was laid off from his job. Insurance coverage was also a stressor as needed medications were not covered with off-label use (as is often the case in the younger child and infant); transport between facilities are also not always covered if it is only for parent/family convenience as was the case with one out-of-state move.

P8 described this experience as follows:

Regardless, we have to fly {} to {} family's new hometown} via a medi-ambulance of some sort. Even if we spent the full month here, she will not be allowed to fly with a fresh trach, and there is no way in hell we can drive cross country with her (the doctors won't even give that one a consideration). The doctors say they think the flight is around \$10,000, but my dad called me tonight to tell me he looked it up and it is around \$25,000 or so because flights require a nurse and a paramedic. We need to find a way to fly her (and me) to {} regardless of what we do. How the hell is this going to work out, I have no idea.

Another concern related to home life has to do with other children in the family. Of the 14 bloggers who identified that there were siblings in the home, 11 of them indicated stress related to the needs of those children. The words of P2, a parent of a child in the NICU, represent the words of many of the bloggers: "I feel very torn between her and {} other child} right now and guilty for not being in the opposite place."

**Responsibility.** Eighteen of the bloggers referred to responsibility as a parent as being stressful. This sub-category included providing normal care to the child, decreasing technology and support as the child's condition improved, and preparing for discharge home. Common practice among the majority of nurses in pediatric areas is to allow the parents to provide care such as bathing and diapering for their child when it is safe for them to do so, with the goal of allowing them to assume a more normal parenting role. However, 13 of these blogger identified providing that normal care as stressful. The parent of a premature infant who was now 58 days of age said this: "Another thing on the agenda today is I am giving him a bath for the first time. I am scared. He won't be submerged or anything like that but navigating around the respirator can be nerve wracking."

Decreasing levels of monitoring and intensity of care were also identified as stressful by over half of these parents. As they are immersed in the medical world, they become accustomed to having monitors to tell them when something is not as it should be with their child. This often

leaves them feeling inadequate to recognize important changes in their child's condition on their own. This can also occur with transfer to a unit as the child is improving; the new unit may utilize a different staffing pattern with more patients per nurse, and the parent feels that their personal level of responsibility is increased. The mother of a premature infant (N11) wrote this:

I was a little emotional all day...now my role as a new mom is here. Each nurse here has 3-4 kids to watch so the ICU care that I was used to (1 on 1) is spread thin here. I was a little overwhelmed with the feeling that if I'm not here with her, no one will be.

Half of the bloggers identified preparation for discharge and assuming increasing responsibilities as a stressor. The parent of a child who had undergone heart surgery (C12) described the increased responsibilities related to her child's medications:

Lola has LOTS of meds this time. Going from only aspirin before surgery to taking 6 is a big change for us. Getting used to that schedule is going to be tricky...she's taking Captopril (heart med, ace inhibitor 3x a day, Lasix (diuretic) 2x day, Prevacid (for reflux) 1x day, Aspirin (blood thinner) 1x day, Sulfamethoxazole (for kidney prophylaxis) 1x day, Tylenol (pain med) every 4-6 hours, and she has a Hydrocortisone cream for a rash she got from the chest leads. Whew!

Even though the parent is clearly seeking to understand the medications and their importance, and is taking on the language and abbreviations of the medical world, she is expressing the stressful nature of this increased level of responsibility.

Stresses related to discharge also include preparations not completed prior to the premature delivery of their child. N2 stated "right now the time drags...but also goes by really fast as far as getting things ready for her to get here (we still don't have a carseat, need a clean house, need to finish her room, etc.)."

A final sub-category of parenting-related stressor is that of empathy for other parents. Sixteen of the bloggers identified stress related to the experiences of other parents they encountered both in the units where their child was a patient and virtually through blogs or other social media. Sometimes a child in close proximity to the blogger's child had a significant event

while they were present; following is a description of such an event by a mother of a child awaiting heart surgery (N17).

As I held my baby close and whispered in his ear that it won't be long, I heard a lot of commotion in the next bed. Our friends {} and {}, who we met whilst on the ward had a little boy 1 week younger than {blogger's child} named {}, he had already had the Norwood procedure and was doing amazingly well in recovery. I looked round and saw a very grey and floppy {other child} in {other mother}'s arms. He had gone in to cardiac arrest, the doctor's rushed over and after a long 20 minutes they had {} stable and back in PICU on a ventilator. It was horrendous and my heart ached not only for {other mother} but for what we may have to face if things go wrong in surgery. Then literally 2 minutes later, a doctor came over and said 'right, we are ready for you...'

Parents also experienced stress when a child other than their own received a new diagnosis. The parent feels empathy for what they are going through, but they also fear the same for their own child. The mother of a premature infant (N14) wrote about this experience, sharing the following:

There is another blog mom of preemie twins that has been visiting my site, and sadly, one of her twin daughters has been diagnosed with Cerebral Palsy. My heart just goes out to her and her family. It has made me afraid of what the future holds for {}. She didn't find out for months after her girls came home. It's terrible, because she is going through so much and I'm not so worried about my daughter.

This quote also demonstrates the bonds that can develop through the Internet and other social media, as the blogger is describing her relationship with someone she knows only through the blogging experience.

**Self-related.** Another category of stressors identified by the bloggers was related to their own physical and emotional well-being. Thirteen bloggers discussed stressors related to their personal health and physical exhaustion, and fourteen described emotions as causing stress.

**Physical concerns.** These stressors were related to the health of the parents. Of the eight bloggers who reported stress related to physical health, half were the mothers of premature infants who still had residual health concerns related to their pregnancy and the other half



developed an illness while their child was hospitalized. Illness kept the parents from being able to visit their children, and in some cases raised concern about worsening the child's illness. N2 shared this: "Hoping I am not getting sick. I have not been feeling well today, so I only went to see {} once. Now, I am not sure I should have gone at all. Pray that I did not get sick germs on her." In another blog, the author shared that the illness of one of the parents caused them to lose their room at the Ronald McDonald house since there are families of immunocompromised children there and stated "one stomach bug, and poor fella is suddenly homeless and no one is willing to come within 6 feet of him!" Physical exhaustion was also a source of stress for 11 of the bloggers. A mother of a child undergoing surgery (N18) said "Pray also for rest for {father}, my mom and myself, as the constant driving back and forth to the hospital is starting to take a bit of a toll on all of us."

**Emotions.** Although there is a component of emotion to many of the themes surrounding this data, quotations related to this code described specific types of emotions that the bloggers related to stress. These included feelings of isolation, emotional exhaustion, guilt, loss, and conflicting emotions. One mother described it this way: "While I was visiting with {} today, I had a bit of a meltdown. I cry fairly regularly these days but I usually try to contain my tears in public. But today I just couldn't keep them in" (N16). A mother of a child in the PICU (P7) summed her feelings up by saying "I am processing a lot of emotional poop right now."

Two of the bloggers delivered twins but only one of them survived. These bloggers both shared their conflicting emotions of grieving for one twin while trying to maintain hope for the survivor. Multiple segments of text from these two blogs were coded within this sub-category.

One of these mothers wrote the following about her emotions:

I was asking Him to show me why He would have me feel like I was mourning alone. This is how I felt from the moment I got home 3 weeks ago. I was angry that my husband, parents, and best friends all got to hold my son and cry together, and I didn't get to be a part of it because I was recovering...and very drugged up for about 3 days. I didn't get to "feel" with them. I didn't get to cry over my dead baby boy with the people I love the most." (N3)

The other mother who lost a twin also expressed stress associated with mixed emotions. She shared the following:

{Father} asked me how {expired twin} would want us to feel. He felt that she would be happy to know that her sister was improving. He's right, but why is this so hard? Why am I so afraid to feel a sense of hope? I really, really feel like I'm being disloyal to my other daughter that is no longer here." (N14)

## **Research Question 2: Coping Strategies Identified**

Using the TMSC as a framework, the blogs were analyzed looking for examples of coping by the parents. Emotion-focused and problem-focused coping mechanisms were identified then further refined and categorized by themes. Table 1 shows the themes and sub-themes of coping strategies identified in the blogs with the number of data segments identified for each theme and sub-theme.

**Emotion-focused coping.** Emotion-focused coping activities involve an individual's processing and expression of feelings that are present in response to a stressor. Emotion-focused coping is more likely to be undertaken in situations where an individual feels that they do not have a lot of control, i.e., they are an effort to ameliorating negative feelings associated with stressful events. Examples of emotion-focused were frequently noted in the blogs used for this study. After the initial coding, was completed, these codes were examined and grouped under

Table 1. Themes and Sub-themes of Coping Strategies Identified by Parents

Emotion-focused coping strategies (1,223)		Problem-focused coping strategies (933)	
Sub-theme	Coded segments	Sub-theme	Coded segments
Accepting	135	Creating	270
Avoiding	36	Providing	248
Maintaining Hope	287	Seeking	280
Reframing	593	Taking	135
Utilizing Logic	118		
Valuing	54		

like themes. The themes of emotion-focused coping identified were: *Accepting, avoiding, maintaining hope, reframing, utilizing logic, and valuing*. A discussion of these themes with examples from the data follows.

***Accepting.*** When using this type of coping, bloggers expressed that they were choosing to “live in the moment” or “take one day at a time. It implied an active process of accepting their reality and trying not to look too far ahead at what might happen in the future as a result of their child’s hospitalization or illness, and appeared to be an effort to control negative emotions and thoughts. This type of coping was noted in all twenty of the blogs. A mother described it in the following way:

So we have a long road ahead of us but for now we are just going to enjoy the moment. This experience is most definitely an advanced course in how to take one thing at a time and how to experience life as a day-by-day journey instead of constantly looking too far down the road. (P5)

This form of emotion-focused coping was applied in a global sense to the overall experience of the hospitalization as well as to specific events and stressors. The following two excerpts demonstrate this contrast; in the first example this coping style is applied to the experience of having a premature infant, while the second mother is discussing a particular stressor (breastfeeding). “It’s different than most first parents experience, but it’s our story. And every family’s story has the beautiful mixed in with the messy at one point or another. Choosing to embrace that is the key.” (N3) “The good news is that both children ‘get it.’ The bad news, or actually the typical preemie news, is that it’s going to be a while before they are strong enough to breastfeed for most of their feedings And you know what? That’s absolutely ok” (N6).

Another phrase seen frequently with this type of coping is “wait and see;” Nine of the bloggers specifically used these or similar words when describing their coping efforts. They functioned as a kind of placeholder; the blogger is aware of a stressor such as potential complications, but is choosing to defer their emotional response until the potential becomes reality. In discussing the possibility that her child may need to have a gastrostomy tube placed, one mother said:

We are just going to see how things play out, and it’s an option later on if we need it. Hopefully, {} can grow by eating from the ng for now, and then...whatever we decide to do to treat the stricture (narrowing) in his esophagus. (N3)

*Accepting* also occurred when the beliefs of the blogger were confirmed; when this code was applied the blogger expressed that they were right about something or things worked out like they thought they would. One mother wrote about this after her child underwent a tracheostomy, stating “I have always had the feeling that if we get the trach things are going to change for the better and they have” (N1). These types of quotes express an acceptance of reality.

**Avoiding.** A second category of emotion-focused coping from the data has to do with avoiding; some bloggers described doing something to keep from thinking about their current situation. This did not represent a denial of their reality, but rather a choice to escape from it for a time. After hearing of a new complication, a father described their response: “We’re kind of hiding out at home and don’t check emails or answer the phone most of the time” (N14). Another type of avoiding occurred in the form of wishful thinking---the blogger expressed a desire for a different reality, in a kind of mental escape. Here are one mother’s words: “I had a vision of {} dancing one day and laughing – what a sweet moment that will be!” (N3). Another mother who’s child was in PICU and heavily sedated said “I would give anything right now to be able to just see her look at me and smile” (P8).

**Maintaining hope.** Eighteen out of 20 bloggers utilized maintaining hope as a way to process their feelings related to their child’s hospitalization. One way parents did this was by anticipating the future. This allowed the parents to focus their thoughts and emotions outside of their current situation. Sometimes the parent was focused on a specific event, as with this mother who talked about anticipating her daughter’s discharge:

Sill no word on discharge. She had an event during her bottle feeding this evening which means she won’t be discharged tomorrow since they would like her to be 24 hours event free before she comes home. Maybe she will come home on Friday and give her big sister {} the best birthday present ever. (N16)

This blogger, writing from the perspective of their premature infant, was looking farther into the future: “Dad said that he had been looking forward to points in my life where he could be proud of my achievements like crawling, walking, talking & becoming the 2<sup>nd</sup> female prime-minister ;-)” (N10).

Another form of maintaining hope seen in the blogs was *expecting the best outcome*. Data from 18 of the blogs were coded with this subcategory. This coping mechanism utilizes an

active choice to hope for the best outcome rather than focusing on less optimal options. The mother of a premature infant who experienced a small intraventricular hemorrhage said the following: “Her head scan came back still showing a small grade 1 bleed, but it was a little smaller than the last scan so that is good. We are hoping that it will be gone soon.” (N2) The mother of an infant diagnosed with a patent ductus arteriosus also expected the best outcome for her child when she wrote

So far, the signs are good: the murmur that let them know it was there has not been heard since the first treatment. Should the echo cardiogram show it’s gone, she gets to start eating again and I think she’ll start on a quick recovery, just like her brother. (N6)

Some parents described how they looked for meaning in the events around the hospitalization, and used their interpretation of these events to maintain hope for their child. The following excerpt is from the blog of a mother who delivered twins but one twin died shortly after delivery.

{Twin A} was a fighter. I felt her move and kick inside me all the time, even more than I felt {Twin B}. That was probably because she didn’t have any fluid around her for 10 weeks. She saved her sister. The doctors told us the change of keeping my pregnancy was slim after {Twin A}’s water broke at 16 weeks, 6 days. She lasted exactly 10 weeks until I was 26 weeks, 6 days. {Twin B} needed that time so that she could be with us today. {Twin A} saved her sister and we will make sure that {Twin B} knows she has a twin sister looking out for her in heaven just as she looked out for her inside me.(N14)

*Prayer and trust in a higher power* was also identified in blogs and functioned as a way of controlling the emotions related to the child’s hospitalization. Descriptions of faith and belief in God were evident in 13 of the blogs; if a blogger openly discussed their spirituality in their writing they were more likely to describe prayer and trust in a higher power as a way of coping. Some prayers were asking for help in controlling the emotions of the blogger such as this one written by one mother: “I know God wants me to be in the moment now though, and I’m praying for the grace to do that each day.” (N3) Other prayers were for the child or for the doctors or

nurses caring for the child. This blogger wrote “Praying that {} hasn’t aspirated, that he isn’t refluxing, that he will continue taking his bottles, that his surgery will go well, that he will have good nurses the next couple of days...” (N9).

**Reframing.** Reframing consists of restructuring the information at hand in a new way to provide a more positive outlook on present events. One way of doing this seen in the blogs was highlighting how much better the child is doing now than earlier in the hospitalization. A mother wrote the following words on the 54<sup>th</sup> day of her child’s hospitalization:

There haven’t been any major changes to her care and we don’t anticipate there being any in the near future. Sometimes it feels like the progress is slow but then we look back on her first day of life and remember how far she has come. (N16)

Another similar coping technique is *looking for positives*. All of the bloggers wrote about this at least once during their child’s hospitalization. When families are so desperately wanting their child’s condition to improve, even the smallest changes are viewed through a lens of optimism, as is illustrated in the following:

He is taking his feedings like a champ. The 4 cc’s are all being digested – great news. He had gone from weighing 1.130 kg’s on Sunday to 1.133 kg’s yesterday – tiniest bit of weight gain, but still a weight gain...(fyi – both of those kg’s translate into the same thing = 2 pounds 8 ounces...but it counts). (N15)

The same blogger utilized reframing again when describing the results from a CT scan on her son by saying “The ventricles have gotten bigger. Not great news. But the clot is getting smaller. Good News. The fluid has not backed up outside of the ventricles. Good News. There are no new bleeds. Good news.”

*Expressing gratitude* is another form of emotion-focused coping under the broader theme of reframing. Similar to looking for positives, the bloggers located something within their situation to be grateful for, and turned their focus to that rather than the more negative aspects of

the child's current status. This mother who delivered twins with one dying shortly after delivery, wrote:

But I'm thankful that I get even this little piece of motherhood. Some women hope for children of their own to nurse or pump for and never get the chance. God has blessed me with a baby boy right now, and I am his mother right now even though I can't hold him, or do much of anything for him, I can provide him my milk and store it up for his future. And that's a blessing. (N3)

There are many things this mother could focus on at this moment: her son who died, the critical condition of the surviving twin, the fact that she is unable to hold her infant. But she is making a choice to move her emotions to a positive state by being thankful for what she has. Twelve of the blogs had instances of this type of reframing.

A group of sub-categories was noted having to do with assigning the responsibility for the outcome of situation to the child. Assuming that the child was able to control a situation seemed reassuring to the parents as with this quote about a child with a significant arrhythmia: "When they began to talk about defibrillating him, he suddenly converted again. Apparently he got the memo, and fixed it himself" (C13). The mother of a premature infant who needed to be able to take all her feedings by mouth before she could be discharged said "I keep telling my little girl that if she only eats all her milk she can come (but she's not listening to me) :) I guess that starts early" (N14).

Believing in the strength of the child is a similar form of reframing, and was noted in 14 of the blogs. As with assigning control to the child, the responsibility for an outcome is placed with the child and helps the parents have a positive outlook---their child is strong enough to overcome any obstacles. These words were written by the mother of a 4 month old scheduled for heart surgery the next day: "Of course I've shed my tears throughout the day but know in my heart that all will turn out just fine. I know my little girl is a fighter and is strong" (C12).



*Humor* is a common coping mechanism among nurses and hospital staff; outside the medical world they would not be thought of as funny but when surrounded by suffering and pain sometimes a lighter approach is needed. Parents participated in or even initiated a reshaping of events in this manner in 13 of the blogs. After finding that a bouncer seat was soothing to her son who was suffering from narcotic withdrawal after heart surgery, a mother said the following:

And in humorous news (hey, we have to find it where we can)...basically when my kid is being soothed by his bouncy seat, it's because he's so strung out he needs a hypnotic distraction. I swear, I could make so much money setting up a rehab program for cardiac kids post-surgery (either that, or patenting the bouncy seat for adults)! (N18)

The final sub-category of *reframing* occurs when parents look for “normal” within the experience of the hospitalization. Behind the tubes and wires, parents focus on a glimpse of a normal child or a normal parenting experience. A mother shared this on her son's 42<sup>nd</sup> day of life after watching his endotracheal tube holder changed:

This was the first time I was there to see them do it and so I finally got to see his mouth for the first time since birth (and that was just a quick flash). He is so much of a little clone of {the father}. I think all he got of me is his eye shape. (N1)

Another mother wrote, “It's hard to tell because it's a dark picture...but {} is sucking on a pacifier – a little bitty pacifier. He doesn't quite get how it works yet and he can't keep it in his mouth, but he's working on it” (N9).

***Utilizing logic.*** All 20 of the bloggers used this emotion-focused technique. It was a way of stepping back from the emotions of being the parent of a hospitalized child and using logic and rational thinking to explain the child's current condition and/or predict the future. These data segments included phrases like “not uncommon,” “not unexpected,” and “could be worse.” This view of their child's illness was shaped from what the parents had been told by health care professionals or other parents who had been through a similar situation, and served to reassure

the parents that things were progressing in a normal fashion. Following are two examples of this coping mechanism:

It's tough seeing her in pain, but we know it could be so much worse and we count our lucky stars. They say the headache last for about a week then they're good to go. Just takes some time to adjust to the new flow and pressures. (C12)

So while the intubation was a bit of a disappointment, I am trying to focus on the fact that {} still is doing better than most other babies her age. It's still not easy, but there is comfort in knowing that. (N16)

**Valuing.** Blog data were coded as valuing when the blogger attributed another individual or group of individuals with contributing positively to their experience and/or their child's well-being. One mother said it this way:

A number of the same people who saved his life then were here tonight when he came off the vent. And actually, that was somehow comforting. The folks who were doing chest compressions two weeks ago were watching over and cheering him on tonight. The same doc who intubated him on that awful, horrific night was the one who removed the breathing tube. And she was wearing his hammer silly band alongside the very rare blue hippo that her son (also named {}) gave her. She's got a *very* special place in our hearts. (C13)

Another mother valued a trusted familiar staff member, saying "My friend {}, who is a nurse practitioner in the NICU has been making sure that he gets the best of the best.... Having her check him out and tell us that he really is doing great is so reassuring" (N15). Bloggers also valued their partners as with this mother who said "{the father} and I have talked about how we are both going to be working together with our son on this journey" (N1).

**Problem-focused coping.** Although not utilized as often as emotion-focused coping by most bloggers, evidence of problem-focused coping was noted in the blogs. With problem-focused coping, active strategies are employed in an effort to mediate or resolve the stressor. Problem-focused strategies that were identified in the blogs fell into four sub-categories: creating, providing, seeking, and taking. Further description of these categories follows.

**Creating.** This occurred when the parent took steps to design their child's environment in a way that mediated the stress the parent was experiencing. One way of doing this was by creating a more normal family setting within the restrictions and responsibilities of having a hospitalized child. The mother of a premature infant described her plan for these efforts, saying "Time to find a new routine and a new "normal" for the next couple of months" (N2). Another described her efforts in more detail:

After a while, the nurses left us alone, and then came back later to check on us and we just started talking with them. The best part to me was sitting in a rocking chair, rocking my baby, while we talked to them. It was just a few moments of normalcy...a normal mommy rocking my baby while talking to friends. (N3)

Another method of *creating* involved efforts undertaken by the parents to become experts on their child's medical condition and plan of care. This helped their coping by equipping them to understand conversations with the health care providers and make informed decisions about their child's care. One mother said this of her efforts: "My perspective on what is "normal" and the "right path" for preemies is evolving and is not even close to the same for what happens for term babies" (N6). These active efforts restored some sense of control to the parents, and many of the bloggers offered accurate detailed explanations of complex medical conditions as well as links to other sites with further information, as with this blogger after his son's open heart surgery:

He has a nice shiny new valve, which wasn't our ideal outcome, but Dr. {} was able to put it in the normal valve space which is very good....Wanna see one in action? [hyperlink] That's not exactly like his, but it's pretty similar and you can see how an artificial valve works. (C13)

**Providing.** In this form of problem-focused coping, the bloggers described different ways of providing in an effort to mediate stress. *Providing care* and *physical contact* to the child, *caring for self*, and *providing information* were variations of providing that were noted.

All twenty of the bloggers described *providing care* to the child as producing positive emotions, like this parent who said

When we got to the hospital, I got two words out about how badly I wanted to hold him before I started crying again and she handed me the Kleenex and told me I could take the side of the incubator down and just sit next to him and put my arms around him. It was amazing. I was pretty much eye level with him, and he was awake and alert...so I laid my head next to his and just talked to him for like an hour until he fell back asleep. It was exactly what I needed – to be able to connect with him like that. (N18)

*Providing information* also served as a coping mechanism. Six of the bloggers explicitly stated their reason for blogging, and it included being able to provide information to friends and family. One mother described the positive effect blogging had for her: “Writing our story has been therapeutic for me. It gives me a connection to the outside world” (P20).

**Seeking.** Some of the bloggers took an active role in finding help in managing their stress. Different sources of help included *learning about others’ experiences, someone to talk to, seeking information, social/structured support* and *tangible help*. In describing learning about others’ experiences, one mother (C13) said this:

I’ll end this tribute to my people with this story from one of my favorite blogs, Adventures of a Funky Heart (a fantastic resource on congenital heart disease). He was talking about the importance of finding support from other heart moms, and that’s hugely important. But whether or not your sustainers have been in your shoes, finding people who will take on your hurts as their own makes your burden bearable.

Although many units and children’s hospitals provide support groups for parents, none of the bloggers in this study mentioned attending a group of this type. The social support they described occurred in more informal settings such as the waiting room of the unit or at the Ronald McDonald House. One mother expressed her appreciation for the support she was receiving through the blog, stating:

I am always amazed to watch my blog counter go up and up as so many of you log on daily to check in on {}’s progress. There have been 8,500 views of my blog since its inception. Amazing. Thank you so much for all of your support. (N14)

Another blogger describes seeking support in a virtual format: “I just read 2 emails from my fellow PROM moms (I am a member of an on-line support mailing list for PROM moms) that I found really touching. Here is a link to that support group [hyperlink]” (N14).

Thirteen of the bloggers described seeking spiritual support as a way of coping, and all of these bloggers described spiritual practices consistent with Western Christian religions. As opposed to trusting in a higher power (an emotion-focused coping mechanism), someone requesting prayer or spiritual support is taking on a more active role and making requests related to specific concerns. An example of these came from the mother of a premature infant:

Prayer requests: Eating...hoping she gets better and better so we can come home! That she will tolerate her vaccines okay and not get a fever or have to be on the nasal cannula at all or for very long. We will have follow-ups on brain scan and eye development coming up...hoping all is good. Patience and rest for us. (N2)

**Taking.** This type of problem-focused coping was noted when a parent decided to actively take control of a situation. This can involve the parent choosing to stay with the patient, or remove himself or herself from the room or hospital. A blogger described taking control in this way as follows: “Today I took a break from driving to the city and going to see {}. I miss her so much...but I actually don’t feel guilty (for the first time in a while). I needed a break...which allowed me to get some work stuff done” (N14).

Parents described taking control of the infant’s care or environment. Fourteen of the bloggers wrote about instances where they asserted control in the hospital environment, like this parent who said “We went yesterday at noon so that we could give her a tub bath. She had already had a couple, but we missed them so we made a point to tell them to wait until we were there yesterday” (P3).

### **Research Question 3: Changes in Stressors and Coping Strategies during the Child's Hospitalization**

In all of the blogs studied, parents identified stressors as well as strategies utilized to cope with these stressors. Both emotion-focused and problem-focused strategies were noted in all blogs; 16 of the blogs contained a greater number of emotion-focused codes. Most blogs had a cluster of information-related stressors at the beginning of the account of the hospitalization with stressors outweighing coping strategies at that time. As the hospitalization continued, stressors that were identified by the blogger were followed by text in which coping strategies were described. In the blogs with a higher number of emotion-focused codes, early strategies were mostly emotion-focused with problem-focused codes appearing as the hospitalization continued. Stressors persisted throughout the hospitalization in all of the blogs. As discharge approached there was often another small cluster of information and parenting related stressor codes.

An example of this can be seen in N9 (premature infant, hospitalized for 125 days). In the first entry on the day of admission, seven stressor codes were applied to the data. Three of these related to role alteration, two to the appearance of the child, and one to the parent's emotions. In this same entry, there was one emotion-focused code (reframing) and one problem focused code (providing physical contact). Later that day and into day 2, there were 10 additional stressors and only two emotion-focused codes. Early in the hospitalization, the family was bombarded with information and emotions and has not yet been able to mobilize their resources to cope with these stressors. At one month of age, the coding pattern has changed. The entry for that day contained two stressors (one related to information and one unfamiliar staff) and has 4 coping strategies identified (two emotion-focused and two problem-focused). The parents were able to find ways to more effectively cope compared with the earlier days of

the child's hospitalization. At two months, this pattern had remained consistent with two stressors, four emotion-focused coping, and one problem-focused code being identified in the blog entry. Then, in the last blog entry prior to discharge, there was an increase in stressors mentioned (four, related to information and increased responsibility with decreasing technology) and only one emotion-focused coping code (looking for positives). This pattern was seen in many of the blogs, regardless of the diagnosis or age of the child.

Stressors having to do with information were almost exclusively followed by an emotion-focused code, often within the theme of reframing. Stressors having to do with parent concerns were often followed by problem-focused coping strategies. This pattern was noted regardless of which type of coping strategy was used more often by the blogger.

#### **Research Question 4: Evidence of Appraisal Leading to Coping Strategies**

Although evidence of appraisal was evident within the blogs, it was difficult to apply appraisal codes consistently. Entries in the blogs usually followed a narrative format with a setting of the scene, complicating action, and response noted. The appraisal of what the stressor (complicating action) meant to the blogger was embedded throughout the narrative and difficult to isolate; appraisal occurred as a pervasive ongoing process within the text.

Some appraisals were explicit in the language and able to be coded; several pertained to the child's improvement or forward progress, such as this quote from N1: "He is progressing so well. Every day his numbers are looking better." Another form of appraisal involved approval of self and how the blogger was managing their current situation. As they prepared for discharge, one father (N4) stated "other than the typical adjustments that come with bringing any new baby home from the hospital, we don't seem to be having any abnormal stress about it."

There were also some appraisals of negative emotions and diminished coping. After an unplanned extubation delayed his son's weaning off of the ventilator, he wrote "{Mom} and I have been here since 2:00 am and I'm tired and not very happy (P5)." That quotation also could be coded with the stressor code for *self: physical* as it speaks to the exhaustion experienced by the parents. Another mother described her emotional state as follows: "There are so many overwhelming questions I have had about how to move on from here (N3)." Most often, these quotes were followed by an attempt at coping; in the case of N3 this appraisal of her current state was followed with a segment coded as maintaining hope, an emotion-focused coping mechanism.

### **Summary**

Blogs written by parents during the hospitalization of a child provided insight into their experiences. When using the TMSOC as a framework for analysis, stressors as well as coping strategies were identifiable within the blog text examined. Stressors were categorized into five themes: child, information, hospital, parenting role, and self. Information-related stressors were noted most often---knowing information and possible complications and outcome was stressful for parents, as was things not as expected (child not responding to treatment, adverse effects of treatment).

Both emotion-focused and problem-focused ways of coping were noted in the blogs. Categories of emotion-focused coping included accepting, avoiding, maintaining hope, reframing, utilizing logic, and valuing with sub-categories within each of these larger themes. Patterns of coping could be observed within individual blogs with more parents presenting evidence of using emotion-focused coping strategies more often than problem-focused strategies. Problem-focused strategies included creating, providing, seeking, and taking. The use of



problem-focused strategies increased over time for most bloggers. Although some appraisals were explicit within the text of the blogs, appraisal was an ongoing process that and embedded within the text and structure of the blog postings.

## CHAPTER 5

The purpose of this study was to use narrative analysis techniques to analyze illness blogs authored by parents of an infant or child hospitalized in an intensive care unit to identify stressors perceived by the parents and measures used by them to cope with these stressors. Stressors and coping strategies were identified and then classified into themes. Patterns of stressors and coping throughout the hospital stay were examined, as was evidence for the appraisal of stressful situations leading to coping efforts by the parents. In this chapter the major findings, conclusions drawn from the research data, strengths and limitations of the study will be discussed. Recommendations for clinical practice and further research are also offered.

### **Discussion of Findings for Question 1 (Stressors Reported by Parents)**

Within the blog writings, the parents described numerous stressors related to having a child in the hospital. These stressors were organized into five different themes: child, information, hospital, parenting role, and self. The most frequently coded theme was stressors related to information. Parents with a child in the hospital are continually receiving information about their child's condition, so this finding is not surprising. The most frequently coded sub-categories had to do with information that was known and information that was not as expected. There are several possible reasons for this. In the current age of more informed consumers of health care, parents are have access to information about their child's condition from a variety of sources. Many units try to include parents in multi-disciplinary rounds, social media provides

access to stories of families in similar circumstances, and Internet searches can provide a variety of resources to learn more about diseases and outcomes.

This information helps with planning and decision-making, but knowledge of adverse outcomes and potential complications associated with critical illness is also a source of stress. Parents identified understanding the plan of care as a problem-focused coping mechanism, but when the child's course of treatment or response deviated from the plan, the parents also identified things not as expected as stressful. These types of stressors are difficult to reduce, as it is necessary for parents to be as informed as possible; deviations from the parents' expectations are often unavoidable and driven by the condition of the child. It is important to offer the parents opportunities to discuss their child's condition and to be cognizant of language used when parents are involved in bedside rounds. One parent offered this insight related to not being given all the information at one time:

Thank GODDESS no one mentioned this [Type 1 Diabetes] to us until the pneumonia resolved. If I had to be dealing with that issue along with {}'s lack of progress, my head would have POPPED off my body and spun around the Pediatrics ward like an over-aged Medusa. (P7)

Being sensitive to how much information a parent has received and their readiness to receive more information is an important skill when dealing with individuals in crisis.

Waiting is another information-related stressor that was identified by almost all of the bloggers. Waiting was classified as information-related because when a family is waiting for results or waiting during a procedure they are often aware of differing trajectories based on the information obtained.

Among hospital-related stressors, system issues were most frequently identified. These included changes in the child's location; these findings were consistent with those of Colville et al. (2009) and Hall (2005). Although moving the child is sometimes necessary for specialty

services or changes in level of care, providers should consider trying to limit moves for staffing or convenience when possible as parents in this study identified all moves as stressful regardless of the reason for the move. It is also important to prepare parents for pending moves and allow them to familiarize themselves with the new area as possible.

Sights and sounds of the hospital such as monitors alarming and lights flashing were identified as stressful in only six of the blogs (five parents of a premature infant in the NICU and one parent of a child in CICU). This was identified as a source of stress in the classic work of Miles, Funk, and Kasper (1992) and has been replicated in more recent studies (Busse et al., 2013; Sweet & Mannix, 2012) using the Parental Stressor Scale: NICU developed by Miles, Funk, and Carlson (1993). Interestingly, the parents who did mention the alarms and monitors as disturbing did not refer to them early in the blog as one might expect as they were becoming familiar with the unit's environment, but later in the hospitalization as they were watching/listening to the monitors for specific parameters which had meaning for them in relation to their child's condition (e.g., decreases in heart rate, respiration and oxygen saturation).

Miles et al. (1992) also identified the appearance and behavior of the child as a stressor for the parents. Fifteen of the blogs used for this research identified the child's appearance as stressful, and seventeen identified the child's behavior or discomfort as stressful. Although not identified as frequently as information related stressors, the findings of this study support the findings of Miles et.al.

Alteration in the parenting role was also identified in a majority of the blogs. Parents were empathetic regarding the experiences of other families in close proximity to their child or whom they met through their accommodations while their child was hospitalized; parents reported stress related to other's experiences in sixteen of the blogs. The bloggers reported

strong emotional responses to observing the anguish of other families; it may be appropriate to provide counseling or at least an opportunity to debrief for families who witness these events. Not being allowed to hold or touch their child had been shown in previous research to be stressful to parents (Briassoulis et al., 2004; Dosa et al., 2001; Uhl et al., 2013); this was also identified as a stressor by the bloggers in this study.

### **Discussion of Findings for Question 2 (Coping Strategies Identified)**

Coping strategies used by parents of a hospitalized child were easily identified in the blogs they wrote. Both emotion-focused and problem-focused ways of coping were noted, and sub-categories within these themes were developed. Themes of emotion-focused coping identified included *accepting*, *avoiding*, *maintaining hope*, *reframing*, *utilizing logic*, and *valuing*. Problem focused coping themes identified were *creating*, *providing*, *seeking*, and *taking*.

*Reframing* and *maintaining hope* were the types of emotion-focused coding noted most often within the blogs used for this study. *Reframing* involves things like looking for positives and comparing where the child is not to where they were, so the focus is in the present. *Maintaining hope* has a future focus; this category includes expecting the best outcome, praying, and anticipating the future. As with all of the emotion-focused coping strategies, the perspective of the individual rather than their reality is what changes. Although health care providers need to be careful not to trivialize the concerns of parents, helping them identify the positives in their child's condition may help them cope with stress.

Among the problem-focused types of coping, those in the *creating* category were most often identified, and the most frequently cited methods were creating a sense of normal and understanding the plan. Being able to create a sense of normal was very important to the parents,

and allowing families to bring in pictures, decorate the bedside, celebrate milestones, and dress the child when possible may help ameliorate some of their stress. Health care providers can also help families by helping them to understand their child's condition and plan of care, and teaching them how to find reputable resources for healthcare information. As previously discussed, providing information can be a source of stress, so evaluating the parent for readiness to learn, learning style, and level of understanding is important.

In 12 of the blogs, seeking social support was described as a way of coping with stress. However, only one of the bloggers mentioned attending a formal support group with other parents in a similar situation. Although it is common practice in many children's hospitals to offer such support groups, it is not known if these types of groups were available to these parents or if they chose not to participate in them. Social support can provide improved resources for coping (Rosenberg et al., 2014), but if currently offered options are not meeting the needs of families then perhaps re-evaluation should occur.

Seeking spiritual support was the sub-category of problem-focused coping with the largest number of coded data segments. However the distribution of coding for this coping strategy was not homogenous; bloggers who utilized this as a coping strategy tended to do so frequently and others not at all. This emphasizes the importance of understanding a family's individual preferences regarding spirituality and spiritual support.

The second most frequently used problem-focused code was providing care to the child; this was noted in 19 of the 20 blogs. Although this code was sometimes accompanied by a stressor code (increasing parental responsibility) it was almost universally followed by a positive appraisal or another emotion- or problem-focused coping strategy. This demonstrates the importance to the parents of being able to provide care to or hold their child or infant.

### **Discussion of Findings for Question 3 (Changes in Stressors and Coping Strategies)**

In the blogs examined for this study, parents reported stressors and both emotion-focused and problem-focused coping strategies throughout their child's hospitalization. In most of the blogs, there was frequent identification of stressors in the early entries at the beginning of the hospital stay. These stressors were often grouped together, without any coping strategies described. When the bloggers did begin describing coping activities related to these early stressors, they were usually emotion-focused.

Another interesting finding was the transition from mostly emotion-focused coping strategies early in the child's hospitalization to an increased number of problem-focused coping strategies later in the hospitalization. Emotion-focused strategies are most useful in times where individuals do not perceive themselves to have much control over outcomes; they utilize emotion-focused strategies to change their way of thinking about the stressor since there is little they can do to change reality (Riley & Park, 2014). As described in these blogs, as the hospitalization continued the parents developed ways of taking control such as creating a more home-like environment for the child, advocating what they think the child needs with health care providers, and seeking out information and experiences of others to develop an expertise in their child's condition. It seems likely that as the parents became more familiar with the hospital environment and accepted norms of that culture, they were able to develop more problem-focused strategies.

### **Discussion of Findings for Question 4 (Appraisal Leading to Coping Strategies)**

Appraisals and reappraisals were more difficult to isolate in these data. The appraisal of a situation was often implied in the description of the stressor or coping strategy employed by the parents. Choosing to write about a specific event is in itself an appraisal of the event as

meaningful to the author; blogging is an ongoing appraisal of an individual's experiences in real time.

When appraisals were identified, some patterns were noted. Positive appraisals, such as good test results or an improvement the child's condition, were noted within the coda of a narrative segment; they were the ending of an entry. Appraisals that were negative did not usually appear at the end of an entry, and were followed by the identification of a more specific stressor or a coping strategy.

This gives support to the appraisal and reappraisal process as described within the theoretical framework of the TMSC. Lazarus (1999) describes cognitive appraisal as a process where an individual evaluates the significance of an event to determine if their resources for coping are exceeded. When the appraisal was evaluated to be positive by the blogger, no further action was needed. With negative appraisals the blogger more clearly identified the source of stress and then employed coping strategies to try to manage the stress.

Often as part of an appraisal, parents commented on things that others did that helped with coping. Having friends and family who were willing to take care of other children and home matters was frequently mentioned. Another specific help was when hospitals or charity organizations were able to offer free or low-cost temporary housing for families with a hospitalized child, and when a staff member (unit secretaries, volunteers, or nurses) was able to assist them in navigating the process for securing a room. Other tangible sources of support that were mentioned included money/vouchers for parking, gift cards and meals. Most bloggers expressed appreciation for visitors, although there were some exceptions when a blogger communicated a desire to be alone. Blogging provided a way for the parents to communicate



these needs to their support network, thus becoming a way of coping (increasing their available resources).

### **Implications for Nursing Practice and Research**

This study demonstrates the immense amount of information contained in blogs written about the illness of an individual or family member. Although the approach for this study was within the framework of stress appraisal and coping, any number of approaches could be taken and would yield a variety of insights into the experiences of patients and their families. Nurses who want to better understand the experiences of their patients and families should read illness blogs---they are publically available and focus on a wide range of informative topics.

Since the early stages of this project, the technology and availability of the Internet and social media has continued to advance. It is becoming increasingly common for families to share their stories on Facebook, Instagram, Twitter, and other platforms. Future studies should include analysis of these platforms in addition to blogs, and a comparison of the types of information shared and perceived benefits could be useful in both understanding the experiences of families and designing interventions to ameliorate stress and help with coping.

The results of this study give us a better understanding of what is stressful to parents and what they do to cope with these stressors while their child is hospitalized. This information can be used to help parents identify coping strategies and to develop interventions to help parents with coping. Many of the bloggers expressed positive outcomes associated with blogging about their experience, and encouraging parents to blog or at least keep a diary or journal may be beneficial. More research needs to be done into the effects of illness blogs on the bloggers and readers, and how different forms of social media can be used to increase social support for families with a child in the hospital.

One of the interesting findings of this study was related to errors, delays, and how they are perceived by families. Stress could potentially be reduced for families by health care providers giving more realistic estimates of when test or procedures will take place, and having a plan for how and when the results will be communicated.

Although there are instruments available for evaluating stressors for parents with a hospitalized child, further research needs to be done regarding how to measure parent coping during this time. This study has identified strategies used by parents to cope with stressors, and this information could be used to inform the development of an instrument to identify and evaluate the effectiveness of coping strategies for use in a larger population.

Some health care system issues that need further examination are also highlighted in this study. Since hospitals encourage family-centered care and many parents want to stay with their children as much as possible, space considerations should be at the forefront of hospital planning and design. Enlisting community partners to provide affordable temporary housing close to the hospital would be another way to meet the needs of parents who are displaced due to specialty services not being available in their community.

With a large number of bloggers reporting stress related to information and differing opinions among health care providers, careful planning and evaluation should be directed toward family inclusion in multi-disciplinary rounds. Positive benefits have been cited by researchers (Cypress, 2012); but developing ways to provide additional emotional and informational support is also needed to decrease the creation of new stressors in the parents.

Helping families through the experience of having a critically ill child in the hospital doesn't only require formal interventions and protocols; how they were treated by staff

influenced the stress level of parents, which is illustrated by the words of the mother of a child having heart surgery:

It didn't take long to settle in, the nurses and doctors made it easy with how welcoming they were. I'll always remember being pleasantly surprised when we were offered a drink in PICU. It was such a relaxed environment even though babies were all classed as 'critical.' It was a little gesture and a warm smile that made us feel at ease. (N17)

### **Limitations of the Study**

Some limitations were inherent in the design of the study. Small sample size and non-randomized sampling limit the generalizability of the study findings. It was not always known which parent was writing the blog, and in some cases authorship was shared, so gender differences were difficult to account for. Inclusion in the study was limited to blogs written in English and to parents of children with specific illnesses and may not be representative of other cultures or families of children with different diagnoses. Truthfulness of the bloggers cannot be verified, but their stories were plausible and events were consistent with the experiences of families I have observed as an advanced practice nurse. Access to the Internet and a perceived ability or comfort with writing would influence an individual's decision to write a blog; this may represent a bias of affluence or education thus further limiting applicability to all parents with a child in the hospital.

One limitation that can be encountered in qualitative work is related to differences in interpretation of data by individual researchers. Individuals view the data through their own lens, which in turn affects the way data are interpreted. Even with the framework of the TMSC, members within the group of qualitative researchers used to verify coding approached the blogs in unique ways. For example, one researcher has a strength-based social work background; her approach was different from that of the group member who was a grounded theory specialist. While the qualitative researchers who consulted on this study did provide helpful input, the

analysis ultimately was done by the researcher. In future studies a more integral group process throughout the study might provide valuable cross-checking and consistency in the application of codes to the data.

### Summary and Conclusion

Analysis of the blogs written by the parents of a hospitalized child provided insight into the stressors these parents experience as well as ways that they cope with these stressors. Stressors identified were consistent with those in the literature, but additional stressors related to information were reported by most of the parents. Coping strategies could be classified as emotion-focused and problem-focused using the TMSC as a framework, providing health care providers with additional knowledge about how parents cope with the illness and hospitalization of their child. This knowledge can lead to improved ways of helping parents cope and optimization of current services offered to parents while their child is in the hospital.

**APPENDIX A: CONCEPTS OF THE TMSC (LAZARUS, 1999)**

Key concepts	Subtypes	Definition
Psychological stress		Relationship between person and environment that the person perceives as exceeding their resources
Transactions		Personal interaction between the individual and the environment
Cognitive Appraisal		Evaluative activity related to stressors
	Primary Appraisal	Individual's evaluation regarding the significance of an event or stressor; can be irrelevant, benign-positive, or stressful. Stressful appraisals include harm that has already occurred or the threat of harm
	Secondary Appraisal	Individual's evaluation regarding what can be done to control an event or stressor as well as the likelihood of success of these interventions
	Reappraisal	Changed appraisal on the basis of coping strategies undertaken or new information from the environment
Coping		Cognitive and behavioral efforts to manage demands that have been appraised as exceeding the resources of the person
	Problem-focused	Strategies used to directly change a situation
	Emotion-focused	Strategies directed at changing how the individual thinks or feels about a situation

**APPENDIX B: STUDIES INCLUDED IN REVIEW OF PARENTS WRITING ABOUT CHILD'S ILLNESS**

Included Studies	Aim of Study	Design and Data Collection Methods	Participants	Findings Related to Internet Use
Capitulo (2004)	Describe/interpret culture of an online perinatal loss group	Ethnography  Participant observation (online), review of 447 emails over a 3 month period, and feedback about findings via a website created for this purpose	Recruited from perinatal loss listserv, 82-87 members during the time of this study  Self-reported to have experienced perinatal loss (2 males, the remainder were female)	Sharing of stories with those in a similar situation; repository of tangible memories such as ultrasound images, photographs; use of symbols as tangible representation of lost infant; discussion of current events; creation of supportive community; discussion of family relationships
Finlay & Krueger (2011)	Examine the public presentation of the grieving self, and explore emotional/interpersonal processes involved in loss and restoration	Ethnography  Textual analysis of memorial websites created by the parents of an infant who died of SIDS	20 SIDS memorial websites identified via Google searches and from web rings on already identified sites (systematic sampling; every 3 <sup>rd</sup> website was selected prior to examination of the site)	Development of websites represents a process of working through grief and identity reconstruction. Websites also function as real-world memorials similar to a gravesite but providing increased opportunities for communication and development of a supportive network.
Fleischmann (2005)	Examine personal narrative of parents of children with autism to identify coping mechanisms	Grounded theory  Open coding to identify concepts and themes	33 websites published by parents of children with autism; explicit	Websites help to: Diminish isolation (identified as a cause of anxiety in parents of children with autism); contribute to self-empowerment via information collection; provide forum for writing of personal stories; create supportive community

Included Studies	Aim of Study	Design and Data Collection Methods	Participants	Findings Related to Internet Use
		related to coping with the disability of a child followed by axial coding to identify links Textual analysis used to identify narrative components	description of how websites located was not offered	
Gundersen (2011)	Investigates how parents use the internet as a resource in coping with stressful life events (part of a larger study on internet use for information gathering)	Qualitative interviews lasting 1.5-3 hours, coded for themes and compared across cases	10 parents who used the internet as a resource to their child's genetic disorder (3 fathers and 7 mothers); recruited through clinic setting	Internet allowed parents to search for information at their own pace in an attempt to reestablish coherence; provides potential support at a pace set by parents
Heilferty (2011)	Identify narrative about parenting a child with cancer, analyze social interactions occurring within a blog, identify reasons for writing and publishing online	Sequential narrative analysis of blogs for life story, themes, and narrative in interaction	14 blogs written by parents of children with cancer, found via snowball sampling	Actions included reflecting, explaining, reporting, expressing, advocating, archiving. Interactivity themes included co-creation (author/reader influence) & support
Morris (2008)	Describe experience of parents of a premature infant hospitalized in the NICU; assess the role of computer mediated communication in	Phenomenological Inquiry	12 individuals who posted stories on March of Dimes Share Your Story website, utilized archived	Benefits of blogging identified included social support and establishing connections, information seeking and providing, feelings of institutional approval from March of Dimes, method of dealing with negative feelings

Included Studies	Aim of Study	Design and Data Collection Methods	Participants	Findings Related to Internet Use
	parents of a premature infant in the NICU; explore resiliency in these parents		postings; and 26 respondents to a survey posted on the researcher's personal web space within the March of Dimes site.	
Nolan, Camfield, & Camfield (2008)	Identify practical suggestions for improving daily life of families of children with Dravet Syndrome (severe form of epilepsy)	Qualitative interviewing: specific information regarding design and data collection was sparse in this report; was part of a larger study	24 families of children with Dravet Syndrome	Families identified Internet support groups as a way of decreasing stress and isolation and obtaining support: the majority of these families preferred online support over traditional in-person epilepsy support groups
Schaffer et al. (2009)	How do parent authors portray pediatric illness, treatment options, and sources of influence.	Qualitative content analysis; coding based on research questions.	Purposeful selection of 21 websites of families of children with cancer or genetic disease, located via search engines (Google and Yahoo) and children's hospital and foundation web sites.	Experiences of families portrayed in great detail; the sites in this study used persuasive language to describe treatment options; influence of these sites is underappreciated by clinicians and researchers.



Included Studies	Aim of Study	Design and Data Collection Methods	Participants	Findings Related to Internet Use
Scharer (2005)	Examine use of a discussion board by parents of mentally ill young children	Quantitative description of the frequency and type of bulletin board use. The bulletin board was developed to provide support for parents of children in an inpatient psychiatry unit	6 parents of mentally ill young children, selected by convenience sampling; utilized WebTV Internet Service Provider.	Participants averaged 5.2 postings during enrollment in the study (average length of enrollment was ~ 13 weeks). Largest number of postings was in 2 categories: illness concerns and group support.
Strohm (2007)	Examine use of message board for parents of infants with neonatal encephalopathy.	Methodology not explicitly discussed.	18 participants on a message board for parents of infants with neonatal encephalopathy and enrolled in a particular treatment protocol (head/body cooling)	Individual yet shared communication (one person contacting another specific person yet in the public space of the message board); some participants went on to develop their own websites
Van de Velde et al. (2011)	Obtain insight into the intentions of parents of a child with cancer in developing a weblog. Abstract of presentation at the International Society of Paediatric Oncology meeting;	Qualitative interviews of bloggers; transcripts were transcribed and coded.	11 parents with a child in treatment for cancer.	Initial purpose: dissemination of information to family and friends. Other benefits: support and information exchange. Negative aspects identified included comments and criticism and intrusion on privacy.

Included Studies	Aim of Study	Design and Data Collection Methods	Participants	Findings Related to Internet Use
Wade, Wolfe, Brown, & Pestian (2005)	Evaluate efficacy of a web-based problem solving intervention for parents of children with traumatic brain injury	Pre- and post-testing on measures of stress/burden, depression, anxiety, and child adjustment. Intervention was web-based and included a homepage with multiple resources.	8 parents and 6 children with moderate to severe brain injury, recruited from the trauma registry of a children's hospital.	Participants were able to develop a strong relationship with the therapist despite in person contact limited to first visit only.
Weingarten (2000)	Describe experience of the development of a spinal cord injury website	Case report of the parents of an accident victim; included analysis of the website and interview with the accident victim and his mother.	Accident victim and his family.	Initial purpose of website was dissemination of information (specific to the accident victim as well as general information regarding spinal cord injuries); developed into a community surrounding the accident victim and the family. Providing information was also considered to be very important by the family.

### APPENDIX C: BLOG DEMOGRAPHICS

Blog number	Child diagnosis	Parent(s)	Gender	Child Outcome	Siblings	Length of stay (days)	Number of blog entries	Number of quotes extracted from blog	Blog activity	Blog year(s)
1	Prematurity	Both	Male	Died	No	274	63	250	Occasional	2008-9
2	Prematurity	Mom	Female	Survived	Yes	80	20	229	Occasional	2013
3a	Prematurity	Mom	Male	Survived	No	146	56	356	Frequent	2012
3b	Prematurity		Male	Died						
4	Congenital heart disease	Dad	Male	Survived	Yes	11	22	144	Occasional	2009
5	Congenital heart disease	Dad	Male	Survived	Yes	17	24	125	Occasional	2009
6a	Prematurity	Mom	Male	Survived	Yes	24	8	156	Frequent	2009
6b	Prematurity		Female	Survived						
7	Respiratory	Mom	Female	Survived	Yes	7	4	63	Frequent	2011
8	Respiratory	Mom	Female	Died	Yes	43	47	625	Occasional	2010
9	Prematurity	Mom	Male	Survived	No	125	85	707	Occasional	2010
10	Prematurity	Self	Female	Survived	No	44	43	247	None	2005
11	Congenital heart disease	Mom	Female	Survived	Yes	17	15	194	Frequent	2008
12	Congenital heart disease	Mom	Female	Survived	Yes	17	19	216	Frequent	2008
13	Congenital heart disease	Both	Male	Survived	Yes	36	42	293	Frequent	2010
14a	Prematurity	Mom	Female	Survived	No	128	63	311	Occasional	2005
14b	Prematurity		Female	Died						
15	Prematurity	Mom	Male	Survived	Yes	50	31	130	Frequent	2009
16	Prematurity	Mom	Female	Survived	Yes	122	99	270	None	2011
17	Congenital heart disease	Mom	Male	Survived	Yes	44	6	37	Frequent	2012
18	Congenital heart disease	Mom	Male	Survived	Yes	43	42	270	Frequent	2010
19	Congenital heart disease	Mom	Male	Survived	Yes	26	23	123	Frequent	2010
20	Respiratory	Mom	Male	Survived	Yes	14	12	146	Frequent	2013

## APPENDIX D: CODE LIST FOR STRESSORS

Theme	Sub-theme	Number of times code used
<hr/>		
Child	Appearance	42
	Behavior/comfort	111
<hr/>		
Information	Knowing	265
	Not as expected	344
	Not knowing	104
	Waiting	201
<hr/>		
Hospital	Error	26
	Sensory	16
	Staff	73
	System	95
<hr/>		
Parenting role	Empathy	28
	Home concerns	66
	Responsibilities	58
	Role alteration	140
<hr/>		
Self	Emotions	72
	Physical concerns	54
<hr/>		

## APPENDIX E: CODE LIST FOR EMOTION-FOCUSED COPING

Theme	Sub-theme	Number of times code used
Accepting	Live in the moment	30
	Wait and see	27
	Accepting reality	64
	Confirmation of beliefs	14
Avoiding	Escape	6
	Wishful thinking	30
Maintaining hope	Anticipating future	40
	Hoping for the best	95
	Looking for meaning	13
	Praying	58
	Trusting higher power	81
Reframing	How far we've come	38
	Strength of the child	36
	Blaming the child	69
	Gratitude	21
	Humor	100
	Looking for positives	47
	Seeking normalcy	239
Utilizing Logic	Could be worse	35
	Not unexpected	60
	Being objective	4
	Rational explanation	19
Valuing	Partner	12
	Staff relationships	5
	Trusting familiar staff	30
	Trusting pros	7

## APPENDIX F: CODE LIST FOR PROBLEM-FOCUSED COPING

Theme	Sub-theme	Number of times code used
Creating	Mastery of medical information	53
	New normal	44
	Normal environment	90
	Understanding the plan	83
Providing	Care to self	29
	Care to child	133
	Information	61
	Physical contact	25
Seeking	Information	44
	Experiences of others	13
	Social support	34
	Someone to talk to	10
	Spiritual support	153
	Structured help	7
	Tangible help	19
Taking	Where to be	16
	Control	13
	Controlling environment	29
	Negotiating	22
	Pre-planning	16
	Using past experiences	7
	Knowledge of the system	4
	Vigilance	28

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