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"OUT OF THE MOUTHS OF SIBS" . . . A PHENOMENOLOGICAL STUDY OF

THE EXPERIENCE OF BEING

A WELL SCHOOL-AGE SIBLING OF A CHILD WITH A TRAUMATIC INJURY

BY

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Seton Hall University
2011

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I would like to especially acknowledge and thank the 7 siblings who participated in this study and who so willingly shared their thoughts and feelings with me. This research could not have been accomplished without their stories and experiences. I cherish all of their words, and I am honored that they chose to be in this study. They are the most important part of this study. Additionally, I want to thank their parents for allowing the siblings to be part of the study.

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DEDICATION

I would like to dedicate this dissertation to my husband, George G. Bugel, who provided constant support to me throughout my work, and to my children, Gregory, Sean and Mary Catherine Bugel, who gave me endless encouragement.

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ABSTRACT

"*OUT OF THE MOUTHS OF SIBS*" . . . A PHENOMENOLOGICAL STUDY OF THE EXPERIENCE OF BEING A WELL SCHOOL-AGE SIBLING OF A CHILD WITH A TRAUMATIC INJURY

Mary Jo Bugel, MA

Seton Hall University
2011

Background: School-age siblings experience a traumatic injury to their brothers or sisters in unique ways, yet there has been little research undertaken regarding the sibling perspective. Understanding what it is like *to be* a well school-age sibling of a child with a traumatic injury is largely unknown.

Objectives: The aim of this study was to describe and understand the experience of being a well school-age sibling of a child recovering from a traumatic injury.

Method: Phenomenology was the method of inquiry used. Interviews were conducted with 7 school-age siblings ranging in age from 8 to 12 years, audio-recorded, transcribed and analyzed using traditional qualitative techniques (Ely, 1991). Identification of patterns and themes common to the experience were identified and described, and examples of the phenomenon existing in popular culture were sought.

Results: Four main themes emerged: the compassion of the siblings, a difficult experience, changes, and constants. Three metathemes were revealed: the experience is an emotional experience, an opportunity for growth, and a different world for siblings. Support for these themes was found in literary and artistic sources, such as art, songs, books, children's television programming, and on internet sites frequented by siblings.

Conclusions: Eight research-based recommendations are presented for nursing practice.

Key Words: *traumatic injury, accidental injury, injury, experience, phenomenology, siblings, sibling relationship, family, children, school-age.*

Chapter I

INTRODUCTION

Personal Diary

This was recorded in my diary around the time when as a nurse I first started talking to siblings of traumatically injured children:

> I arrived at the children's hospital where I work early this morning. As I exited the elevator, I could hear the sounds of little voices from the children on the patient unit. I wondered what type of day it would be. Walking through the hall I passed the Dayroom and noticed a young girl sitting alone on the sofa. Her facial expression seemed forlorn. Her small wiry frame appeared miniature in stark contrast to the large empty room, where she appeared to be abandoned and lost. The TV was on and its blaring volume filled the room with noise, yet the little girl did not seem to notice. She sat motionless in the corner and stared without focus into the expanse of space in the room. I was immediately taken with her and wondered: Who is this child? Why is she here alone? What is she thinking about?
>
> "Hi there. Are you waiting for someone?" Startled by my presence, she turned toward me. As she lifted her head, her long brown hair fell around her face in striking contrast to her pale skin. The soft curls of her hair surrounded her face and reminded me of a beautiful wooden picture frame on an antique oil portrait. Her looks were classic. Her brown eyes looked up to

> mine, and for a moment I thought I could feel her sorrow. I sensed that this little girl was sad and troubled. She responded timidly, "No, not really."
>
> I sat down next to her and we began to talk. Her name was Deirdre and she was 10 years old. Her older brother is in the hospital here because he was hit by a car a few weeks ago while riding his skateboard after school. She said that he has something wrong with his brain and is still "sleeping." Deirdre came to the hospital today with her mother, who was in a meeting with her brother's doctor, nurse and therapist. She told me that she was thinking about the Girl Scout trip to the Franklin Museum which she is missing today. She didn't remind her mother about the trip, because her mom seemed so upset about her brother's accident. Besides, she thought, it was not right to think about herself when her brother was so hurt. She wondered whether he will ever get better.
>
> It struck me then that I have no understanding, in any real sense, what the experience is like for siblings who have a brother or sister who is traumatically injured. What do siblings like Deirdre experience? What do they think? What do they feel? What is it like for them to witness so closely a medical crisis with their brother or sister? What is it like for them to be part of a family in such a crisis? (Bugel, personal diary, circa 1990)

It was my encounter with Deirdre, and other children like her, that initially sparked my unremitting interest in this real life experience and led me down the path to carry out this research study.

Aim of the Study

The aim of this study was to identify, describe and understand the experience of being a well school-age sibling of a child recovering from a traumatic medical injury.

Ever since 1986, while at my professional job as a pediatric nurse, I have spoken to children who had brothers or sisters who were seriously injured and consequently required an intense course of rehabilitation, nursing care and therapy at a pediatric rehabilitation hospital. These injured children frequently spent weeks and months in a rehabilitation hospital trying to get better. I have seen parents struggle to support their injured, hospitalized child while simultaneously attempting to maintain a sense of normal function and routine in their family life. Sometimes families were successful and coped very well with multiple stressors; sometimes families were overwhelmed and became fragmented and split apart. I observed a wide range of family outcomes. Throughout this family crisis, siblings accompanied their parents and families to the rehabilitation hospital and visited with their brothers or sisters on the clinical units, where I consequently met them.

Many times I engaged siblings, especially school-age siblings, in dialogue. Although much of the time we spoke about trivia, sometimes the discussion focused on what was happening in their lives while their brothers or sisters were in the hospital recuperating. I have long known that these siblings had stories to tell.

This study focused on the experience and perspective of the well school-age sibling of a previously healthy child who recently sustained traumatic injuries. The

well sibling's experience was explored within the context of membership in a family undergoing a crisis that directly affected the injured child and indirectly affected all family members, including the well school-age sibling.

Research Question

What is the experience of being a well school-age sibling of a child recovering from a traumatic injury?

Chapter II

REVIEW OF THE LITERATURE

Introduction

Accidental injury remains the number one cause of disability for children over the age of one year in the United States (Centers for Disease Control & Prevention, 2003) and the number one cause of nonfatal unintentional injury resulting in hospitalization for children 0-14 years of age (Centers for Disease Control & Prevention, 2011).

Considering only one diagnosis among the many comprising traumatic injuries, such as Traumatic Brain Injury (TBI), The Division of Injury Response of the National Center for Injury Prevention and Control of the U.S. Department of Health and Human Services reported: an average of 475,000 Traumatic Brain Injuries has occurred each year from 1995-2001 among children 0-14 years of age (Langlois, Rutland-Brown & Thomas, 2006, p. 8); every year, on average, 37,000 of these children were hospitalized (p.8); and from 3-5% of these children were eventually transferred to short and long-term care facilities (p.27) indicating serious injury. The two age groups at highest risk for TBI are 0-4 year olds and 15-19 year olds (p. 8).

Similarly, from 2002-2006, a total of 473,947 Traumatic Brain Injury-related emergency department visits were reported among children ages 0-14 years of age (Faul, Xu, Wald, & Coronado, 2010, p. 15). Out of these, a total of 35,136 resulted in hospitalization (p. 15). Given that the average family with children under the age of 18 years in the United States currently has 1.92 children (United States Census

Bureau, 2010), there are approximately as many siblings of children in the U.S. with a TBI as there are actual children with TBI. The large number of well siblings under 18 years of age who may be affected by this particular traumatic injury, alone, supports the significance of this study.

Gelmann (2000) described the sibling experience of previously healthy children who were hospitalized with either a chronic illness or injury. Eight of the 10 siblings in her study were adolescents. She identified 7 theme categories: dispirited weariness, emotional turmoil, unrelenting anger, working through parental situation, sense of grief and loss, ways to cope, and uncertainty.

Pit-Ten Cate and Loots (2000) explored experiences of siblings of children with physical disabilities, specifically about their coping skills and relationships with peers, parents and the disabled child. Forty-three siblings from 12 to 18 years of age participated in the study. Findings included: the siblings had no problems with peer relationships associated with having a sibling with a disability; communication with their disabled brother or sister was difficult; the siblings desired changes in their parent relationships, but the relationships were mostly positive; and "the pattern of the use of the coping strategies by children in the sample is no different from that of the other youngsters in this age group . . ." (p. 404).

Morrison (1997) studied self-reported stress in healthy siblings, between 7 and 11 years of age, of children who were hospitalized for various acute illnesses. The illnesses were not described. Findings revealed that 77% of the siblings experienced stress, with children from 8 to 11 years of age having significantly more stress than

the 7 year olds. Siblings who visited their brother or sister in the hospital more often were found to have more stress than those who visited less often. Sadness was found to be a common factor related to stress.

Swift et al. (2003) examined sibling relationships and outcomes for siblings of children with Traumatic Brain Injury. Measures of sibling relationships were evaluated by the siblings, the injured children, and parents. The major finding was that at 4 years post-injury, mixed gender dyads of siblings of TBI children demonstrated more negative relationships than siblings in the non-TBI control group.

McMahon, Noll, Michaud and Johnson (2001) examined depressive symptoms, self-concept, and social and academic behavior in siblings of children with severe TBI. Data were collected from siblings' self-reports, teacher assessments, and the primary caregiver. Findings did not support the hypothesized outcomes of poor self-concept and behavioral problems in the siblings.

O'Hara et al. (1991) explored siblings' and children's concerns related to living with a family member who was a TBI survivor. Three siblings of undisclosed ages participated in an open forum panel discussion, but were children at the time of injury. The panel also included children of TBI patients; that is, these children had parents who had the diagnosis of TBI. Participants, who were adults at the time of the panel discussion, were asked to remember back to experiences they had years ago as children or adolescents. Five themes were identified: more responsibility and less carefree time anymore, each day is a new experience, support and information on TBI

is needed, parents need to support siblings, and community acceptance of TBI is needed.

Gill and Wells (2000) conducted a retrospective study of the experience of living with a brother or sister with a Traumatic Brain Injury. Sibling participants were between 14 and 30 years of age. Only 4 participants were school-age children when the TBI occurred; of these 4, at the time of the interviews, 2 were teenagers and 2 were adults in their early twenties. Themes identified center around: personal changes in the sibling, being forever different, and self-discovery.

Summary

The impact of *chronic* illness of a child on siblings and the overall family system has been described in the literature (Williams et al., 1999; Williams et al., 2002; Guite, Lobato, Kao, & Plante, 2004). Additionally, the psychological and physical effects on well siblings of children *with cancer* have been well studied and documented (Ballard, 2004; Barrera, Fleming, & Khan, 2004; Houtzager, Grootenhuis, Caron, & Last, 2004; Houtzager, Grootenhuis, Hoekstra-Weebers, & Last, 2005; Houtzager, Grootenhuis, & Last, 2001; McGrath, Paton, & Huff, 2005; Murray, 1998; Murray, 2001; Nolbris, Enskar, & Hellstrom, 2007; Packman et al., 2004; Packman et al., 2008; Sloper, 2000; Wilkins & Woodgate, 2005; Woodgate, 2006). Similarly, the effects on well siblings and families of children with chronic disease and disability have also been well studied (Fleitas, 2000; Gelmann, 2000; Guite, Lobato, Kao, & Plante, 2004; Hollidge, 2001; Horton & Wallander, 2001;

Naylor & Prescott, 2004; Pit-Ten Cate & Loots, 2000; Tak & McCubbin, 2002; Taylor, Fuggle, & Charman, 2001; Williams et al., 1999; Williams et al., 2002). However, the findings in these studies are inconsistent and may not be generalizable to healthy siblings of *traumatically injured* children.

Existing research focusing on the experience of the well siblings of children *with traumatic injuries* is sparse; furthermore, there is no research about *school-age* well siblings of *recently* traumatically injured children who remain hospitalized for rehabilitative care. This unique age group of well siblings is experiencing crisis at a personal level, as well as at a family systems level. Their lives are in turmoil, yet the experience of these children has not been studied as a distinct phenomenon.

By focusing on *a different developmental age group*, the previously unrevealed perspective of school-age siblings can be discovered and documented. It is important to study this unique perspective since cognitive abilities and levels of understanding differ from age group to age group (Piaget, 1971/1974, p. xii; Piaget & Inhelder, 1966/1969). Furthermore, Piaget (1951) purports the developmental nature of perception, stating that "comparisons, analyses, anticipations, etc., . . . grow regularly with age" (p. 76).

In Gelmann's (2000) study, criterion specified that the affected children had a prognosis of home care, essentially defining them as "chronically disabled" and thought to "never be the same persons as they were before" (p. i). The prospect of home care was not a criterion in this current study. The traumatic nature of the hospitalized children's injuries, along with families being thrust unexpectedly

overnight into an overwhelming crisis, is a different phenomenon as compared to the ongoing phenomenon of families and siblings dealing with *chronically disabled* children.

In two studies (O'Hara et al., 1991; Gill & Wells, 2000), siblings' concerns were explored retrospectively. Adult participants were asked to remember back to experiences they had years ago as children or adolescents. This is different from the current study which explored siblings' experiences as they were occurring, capturing a phenomenon unfolding. In the study by O'Hara et al. (1991) findings were culled from a small group which encompassed both siblings of a TBI survivor and children with a parent who was a TBI survivor, and did not examine sibling's concerns and issues as a separate entity.

There is a gap in the literature regarding studies which have focused specifically on the well sibling's perspective during the traumatically injured child's recuperative phase, from the perspective of well school-age siblings living through the experience. Without understanding, grounded in the perception of the children experiencing the phenomenon, there is no basis for developing and implementing interventions for nursing practice.

Chapter III

METHODOLOGY

Design and Approach

Phenomenology has been used by nurse researchers as a way of clarifying thoughts, connecting concepts in new ways, discovering new knowledge to help in the understanding of the lived experience, and "describing human experience fully" (Lauterbach, 2007, p. 217). When knowledge about the lived experience is drawn directly from the perspective of the actual people involved in the phenomenon, a more appropriate, responsive and need-fulfilling strategy of nursing interventions can be initiated. Since there is little known about the experience of well school-age siblings of children with a traumatic injury, it is an appropriate methodology to answer the research question.

Van Manen's (1984, 1990) method of phenomenology seems particularly appropriate for the study of children, when compared to other phenomenological methods, because of Van Manen's self-proclaimed interest in the realities and lifeworlds of children (Van Manen, 1990, p. 2). He developed and used his methods successfully to study the experiences of children, giving evidence to the congruence of Van Manen's method and the phenomenological study of children. A description of Van Manen's approach is summarized in *A Methodological Outline for Doing Phenomenology* (1984, p. 5) (see Appendix A).

Following Van Manen's (1984, 1990) approach, I turned to the nature of the experience, investigated the phenomenon as it is experienced, reflected on essential themes, and described the phenomenon through the art of writing (Van Manen, 1984, pp. 3-4). I explored the experience of school-age well siblings, described the experience from their perspective using their words, analyzed and interpreted the data collected from siblings who were actually engaged in the phenomenon, and looked for examples of the emergent themes in literary and artistic sources.

Assumptions, Biases, and Beliefs

Purposeful and mindful reflection by the researcher regarding personal beliefs and biases is essential to the research process of phenomenology. Pre-study identification of the researcher's beliefs is a classic phenomenological method recommended by phenomenologists (Munhall, 2007; Van Manen, 1984). It is crucial that the researcher spends time reflecting upon and pondering preconceived ideas and beliefs regarding the phenomenon of study prior to data collection, document these beliefs, and then set them aside, as much as possible.

To follow this method, the technique of "bracketing" (Ely, 1991, p. 50; Van Manen, 1990, p. 175) was used to reflect upon, identify, and acknowledge personal pre-conceived ideas and assumptions before starting any data collection for this study. When this was accomplished, these ideas were then set aside by the process of "decentering" (Munhall, 2007, p. 170) in order to remain open to the experience and perceptions revealed by participating siblings. "To be truly authentic and effective, the researcher is asked to do something that is impossible to do, but to do it to the

greatest extent that is possible" (p. 170). Finally, as Lincoln and Guba (1985) advise, the pre-study beliefs were later evaluated against the findings of the study as part of the audit process conducted by the Chairperson of the Dissertation Committee.

Researcher's stance.

Siblings have been a big part of my life for as long as I can remember. I grew up with an older brother and a younger sister. My childhood memories are intermingled with so many memories of my siblings—some happy, some not, but almost always full of experiences that shaped and influenced my growth and development. As an adult, I married into a family of 11 closely spaced siblings—5 brothers and 6 sisters born over a period of 12 years. Even today, their complicated adult relationships are rooted in the childhood sibling relationships they experienced. Along with my own 3 children's relationships, I have had the opportunity to observe a myriad of sibling relationships and interactions throughout my lifetime. I find them fascinating and intriguing at the least, and typically influential to one's character and skill development. The nature of sibling relationships has received more attention in recent years and has been studied using several approaches (Recchia & Howe, 2009; Kim, McHale, Crouter, & Osgood, 2007; McHale, Whiteman, Kim, & Crouter, 2007; Richmond, Stocker, & Reinks, 2005). The complexity and importance of research regarding sibling relationships and sibling experiences has been recognized and addressed in the literature. Dunn (2005), an accomplished family researcher, spoke to the importance of sibling relationships and research regarding siblings:

> As a sibling, you grow up with this other person who is going through developmental changes ahead of you or just after you. What do we know about the consistency and stability of the emotional contact between siblings? How do the cognitive changes in both siblings within a relationship affect the quality of that relationship and its developmental impact, for instance, on each child's emotional understanding? How do changes in each child's social world outside the family impact on the intimacy of their relationship? These questions remain tantalizingly unanswered. (pp. 656-657)

I have worked with children and families throughout my professional nursing career in different types of pediatric nursing positions. I have always been an advocate of children, and have a deep respect and appreciation for the needs of all children, especially siblings. In my twenty-five years working with families experiencing a crisis in the aftermath of a traumatic injury to their child, I had the opportunity to speak with well siblings of injured children many times. These siblings shared small facets of their experience with me in a candid way. I came to realize that many siblings have unique needs which get little attention from parents, health professionals, or other caring adults. This phenomenon has long intrigued me, and over many years I have sustained an interest in learning what the experience is truly like for these well siblings. Because I believe nurses could better support well siblings during the family crisis if we knew more about the phenomenon, I remained frustrated in my efforts to proactively support well siblings of traumatically injured children within the context of family health. My fervent hope and desire is for nurses

to truly include siblings in family-centered care, which often only includes the injured child and the parents.

This study was developed and carried out with the intent to use the findings of this study to shape guidelines and establish new standards of care for well siblings, which can be used by health professionals involved in family-centered care of young families with a traumatically injured child.

Personal assumptions, biases and beliefs.

My pre-study beliefs were founded on the supposition that being a well sibling of a traumatically injured brother or sister is a different experience than being a sibling of a healthy child. Similarly, being a well sibling of a traumatically injured brother or sister is a different experience than being a well sibling of a chronically ill or developmentally disabled child. The possibility of the unending nature of chronic illness and subsequent developmental disability is not yet a predictable sequella of the injured child's current health crisis at the time of injury, especially during the initial rehabilitation phase when family hope is strong and focused on the belief that the affected child will return to his or her previous "normal" level of overall functional abilities.

Family Systems Theory (Bowen, 1978) holds that a change in patterns for one member of the family system, such as the traumatically induced pattern changes of the injured child, influences pattern changes in other family members. The well sibling is part of the family system involved in the traumatic crisis. Furthermore:

> It is the nature of a family that its members are intensely connected emotionally. . . . People solicit each other's attention, approval, and support and react to each other's needs, expectations, and distress. The connectedness and reactivity make the functioning of family members interdependent. A change in one person's functioning is predictably followed by reciprocal changes in the functioning of others. (Bowen Center for the Study of the Family, 2000-2004, para. 1)

My personal beliefs are in accord with Bowen's theory. Furthermore, my belief is that Bowen's theory is fitting to the study of this phenomenon and, because of this belief, was used as a general framework to conceptualize the study. Family systems theory provides the justification to study well siblings; it is through the application of this theory that siblings are believed to be affected by the trauma of their brothers or sisters. Furthermore, family systems theory will help interpret and make sense of study findings.

Well siblings experience the crisis and changes in family patterns from their own unique perspective. It seems that there is unrecognized risk or threat of harm to the well-being of school-age well siblings within a family in crisis related to the traumatic injury of one of the children. While Bowen's (1978) model allows for re-patterning of the family, my bias has been that well siblings may be negatively affected in future development and evolving family processes. My belief going into this study was that siblings may experience feelings of sadness, guilt, anxiety, loneliness, and/or anger and resentment. When siblings do not receive active support

from adults regarding such unresolved feelings and emotions, or when siblings are not provided with the opportunity to freely express these feelings in positive ways, they are at risk for repercussions which can affect the siblings' self-esteem and psychosocial development.

School-age children, because of their age-related needs, seem to be at particular risk for unrecognized threats to well-being when compared with older and younger children. For example, Erikson's *Eight Ages of Man* (1950/1963) holds that adolescents have a greater sense of independence than school-age children, and are more readily able to seek out peer groups for support. Younger, pre-school children remain closely dependent on adults for the provision of basic needs, and when a family crisis occurs, it has been my experience that they are more likely to be left in the care of other caring adults. But school-age children, who bridge the adolescent and pre-school age groups, are frequently left on their own during a family crisis, yet they have little access to peers and after-school activities without adult facilitation. During crisis events, parents sometime fail to provide needed support to well siblings while they themselves are coping with the traumatic injury to another of their children. The energy of the entire family system is focused on stabilizing the health of the injured child in the effort to reestablish stable patterns for the whole family system. But with limited access to psychosocial support and increased separation from their parents, well school-age children may be in a state of crisis, albeit unrecognized, and have limited ability to seek out and obtain support on their own. Due to changes in family patterns and increased stress, school-age siblings of a

traumatically injured child are especially vulnerable and at risk for negative psycho-social and physical outcomes, due to the stress related to the injury event and ensuing changes in family patterns.

These beliefs were central to the development of the research question and the research design.

Trustworthiness

Data collection and data analysis were planned and carried out to enhance the trustworthiness of the study findings. Data were collected in a fair, ethical and organized manner, enhancing the *auditability* of the data; and it was drawn directly from the siblings undergoing the phenomenon, enhancing the *fittingness* of the data. By following accepted qualitative methods of data collection and data analysis, the findings of this study reflect as nearly as possible the *essences* of the actual experience of the siblings. By maintaining an awareness of sensitivity, I was able to "see and hear accurately what is reported as data" (Rew, Bechtel, & Sapp, 1993, p. 301) and thereby increase the *truth value* of the findings.

To enhance the trustworthiness of the data, especially related to the validity of the findings, the technique of decentering (Munhall, 2007, p. 170) was practiced before each interview session. This was done expressly for the purpose of remaining open to the words of the siblings, so that I would truly "hear" what the siblings were saying. Decentering was used in order that study findings were grounded in the perceptions of the siblings rather than the researcher's pre-conceived beliefs.

Trustworthiness of the findings in qualitative research is evaluated by four criteria: *credibility, transferability, dependability,* and *confirmability*. Lincoln and Guba (1985) suggest techniques to increase trustworthiness of the findings, many of which were incorporated into the design and implementation of this study.

Credibility and truth value of the data were achieved through private and confidential engagement with the siblings, and supported by the development of trust between the researcher and the individual siblings. Each sibling demonstrated a willingness to share verbal descriptions that accurately described his or her experience; indeed, several siblings were most eager to share their experiences. Since truth is subject-oriented and not researcher-oriented, it is important to note that all of the siblings had ample opportunity to realize that I was truly interested in their perception and description of their experience, and to understand that the research study was about them, and not the researcher. This resolute focus on their experience and their perception was explained to each sibling in very simple, age-appropriate terms during the initial meeting with each sibling. It was explained both verbally and in writing on the Child Assent form, and was subsequently emphasized again at the beginning of the actual interview.

At the beginning of each interview each sibling was respectfully thanked for his or her participation in the study and let the sibling know that by participating in the research, the sibling was playing an important part in helping the researcher and other healthcare professionals to learn what the experience is like for siblings.

Respectful behavior and positive reinforcement generally support a trusting relationship.

Triangulation is another "mode of improving the probability that findings and interpretations will be found credible" (Lincoln & Guba, 1985, p. 305). One way to triangulate the data is to validate the evidence by comparing it to other sources of data. A search of literary and art sources suggesting or representing emergent themes discovered in the data was done and integrated into the findings in an effort to achieve contextual validation and to further support credibility. Data sources in this search included: children's literature; art works; children's television programming, consisting of videos and songs; and child-friendly websites, presenting stories and narratives written by children.

Validity of findings is enhanced by member-checking which "is the most crucial technique for establishing credibility . . . [and which] provides the opportunity to assess intentionality . . . [and] gives the respondent an immediate opportunity to correct errors of fact and challenge what are perceived to be wrong interpretation" (Lincoln & Guba, 1985, p. 314). During the actual conversations with the siblings, member checks were done regularly, mirroring back my understanding of the words that the siblings were speaking, and then asking the siblings if I "got it right." Furthermore, when unclear or unsure of what the siblings were trying to express, the participants were asked to clarify the meaning. Questions were used, such as: "Let me know if I got this right or not. I think you are saying . . . (fill in) . . . is that what you mean? Did I get it right?" This gave the siblings the opportunity to agree with, or

correct, any misinterpretations I might have had about what they were saying. By validating the intent of the siblings' statements with the siblings themselves, the data has become more credible and the true essence of the experience was verified with the siblings who are living through the experience.

The second criterion for establishing trustworthiness is transferability. Transferability can be facilitated by providing the reader with the "thick description(s) necessary to enable someone interested in making a transfer to reach a conclusion about whether transfer can be contemplated as a possibility" (Lincoln & Guba, 1985, p. 316). In the findings of this study, a collection of rich, thick descriptions of *the experience of being a well school-age sibling of a child with a traumatic injury* are presented in two formats: vignettes describing each individual participant's experience; and the emerging themes and metathemes discovered, illustrated with exact quotes from the siblings. These findings were extracted from the descriptive data drawn directly from the siblings' spoken words, thereby enhancing the fittingness of the findings; that is, "the findings of the study . . . 'fit' the data from which they are derived" (Sandelowski, 1986, p. 32). Furthermore, the criteria for the research participants were carefully developed and followed, so that the siblings in the study were, indeed, engaged in the experience regarding the phenomenon of interest. As suggested by Lincoln and Guba (1985), the researcher does not transfer the findings; rather, the researcher provides the data for the reader to make his or her own decision regarding the potential transferability of the findings. This was done for this study.

The third criterion, dependability of the data to support auditability of the findings, is challenging for qualitative researchers because the "uniqueness of human situations and the importance of experiences . . . are not necessarily accessible to validation through the senses" (Sandelowski, 1986, p. 33). However, Lincoln and Guba (1985) suggest researchers can enhance dependability through the use of an *inquiry audit* (p. 317). The audit trail is the researcher's actual documentation and account of the qualitative *process* created during the data collection and analysis and includes process notes and researcher's journal entries. When careful documentation is kept, and when an external auditor using the same data and perspective is able to clearly follow the original researcher's audit trail and arrive at the same or comparable findings, but never contradictive conclusions, the findings are considered auditable and dependable (Sandelewski, 1986). During the planning, recruitment, data collection, and data analysis cycles of this research, the entire process was documented thoroughly in journals, logs and field notes so that dependability would be evident through a terminal audit. Documentation regarding how methodological decisions were made is contained in these journals, and serves as a traceable *decision trail.*

Confirmability, the fourth criterion, is based on the three aspects of trustworthiness: credibility, fittingness, and auditability. Confirmability is about the neutrality of the data and refers to the findings themselves, and can be established by the same audit trail when field notes and journal entries are compared to the data actually collected. "An auditor's first concern will be to ascertain whether the

findings are grounded in the data, a matter easily determined if appropriate audit trail linkages have been established" (Lincoln & Guba, 1985, p. 323). In addition, early disclosure of my assumptions, biases, personal beliefs, and information describing how I came to the phenomenon of interest, is particularized in such a way that it can be evaluated against the research findings to assure that I have not allowed my values and beliefs to undermine the essence of the sibling experience. This information was reviewed by the Chairperson of the Doctoral Committee during data collection and data analysis as an ongoing audit. Additionally, the aforementioned triangulation of the data also supports confirmability.

An additional effort to establish trustworthiness of the findings was achieved through the maintenance of a reflexive journal. This journal "has broad-ranging application to all four areas" (Lincoln & Guba, 1985, p. 327) of trustworthiness. It differs from the researcher's journal and field notes, such that, it is very personal and introspective. This journal is where personal values, interests and growing insights about the phenomenon were recorded, along with personal feelings and reactions.

Participants

The research participants were recruited as a purposeful sample from a pediatric rehabilitation hospital in the Northeastern United States. Inclusion criteria for each *sibling* participant in the study included: an English-speaking, well, school-age child from 8 through 12 years of age, who had a brother or sister who recently became hospitalized following a traumatic injury, and who lived in the same home with the

injured child. Additionally, the sibling could not have caused the injury to the affected child. The *index child* was one who: sustained a *traumatic injury*, defined as an acute, serious, damaging injury threatening the previously healthy child's physical well-being. Criteria included that the injured child required hospitalization to receive a course of acute rehabilitation in order to get well, and could be any age. The seriousness of the injury had to impact or impede the affected child's growth and development in some way, and initiate a family crisis whereby family patterns of living were significantly disrupted causing an immediate and unexpected change in the child's and family's lives. The injured child must have been well and healthy previous to the injury, growing and developing at an expected rate. Excluded from this study was any child whose injury was the cause of either confirmed or suspected child abuse or any type of a violent crime.

Seven well school-age siblings participated in this study. All the participants had a brother or sister who recently experienced a traumatic injury of some type requiring an in-patient hospitalization for a course of acute rehabilitation. These index children were actively in treatment to "get better" and working toward improving their post-injury functional abilities by receiving multiple therapies and nursing care.

The number of sibling participants was determined by the principle of data saturation commonly used in phenomenology (Polit & Beck, 2004). Data saturation occurs "when themes and categories in the data become repetitive and redundant, and no new information can be gleaned by further data collection" (p. 57).

When seeking out participants for a phenomenological study, the overriding aim of the researcher is to find participants who have actually experienced the

phenomenon under study. Generalizability of the findings is not a guiding principle in participant selection; rather, the guiding principle for participant selection in phenomenology is that "all participants must have experienced the phenomenon under study and must be able to articulate what it is like to have lived that experience" (Polit & Beck, 2004, p. 309). Although phenomenologists do not specifically or purposely seek diversity in the participant group, finding participants of diverse backgrounds who have experienced the phenomenon under study is desirable and occurred with this study's participant group. As shown in Table 1, there

Table 1

Age and Gender of Sibling and Index Child as a Percentage of the Sample

Characteristic	Sibling (n = 7)	Frequency	%	Index Child (n = 6)	Frequency	%
Age						
	8	1	14.28	8	1	16.66
	9	1	14.28	9	2	33.33
	10	1	14.28	13	1	16.66
	11	3	42.85	17	1	16.66
	12	1	14.28	18	1	16.66
Gender						
	Male	2	28.57	Male	1	16.66
	Female	5	71.42	Female	5	83.33

were siblings participants of all ages from 8 through 12 years, as well as siblings of both genders. The index children, i.e., the traumatically injured children, ranged in age from 8 to 18 years, and also consisted of both males and females. Table 2 displays: the age differences from sibling to index child, which ranged from 7 years

younger to 3 years older; the total number of siblings in the family, ranging from 2 to 4; and the four categories of siblings' racial/ethnic groups.

Table 2

Family Characteristics as a Percentage of the Sample

Characteristic	Frequency	%
Age Difference:		
Sibling to Index Child		
-7 (7 years younger)	1	14.28
-6	1	14.28
-4	1	14.28
-2	1	14.28
-0- (same age, twins)	1	14.28
+2 (2 years older)	1	14.28
+3	1	14.28
Total No. of Siblings in Family		
2	1	14.28
3	5	71.42
4	1	14.28
Sibling's Racial/Ethnic Features		
Asian, Filipino	1	14.28
Mixed*	1	14.28
White, Hispanic	1	14.28
White, Caucasian	4	57.14

Note. *Mixed = half African American, half White Portuguese

The primary diagnoses and causes of the injuries to the index children are displayed in Table 3.

Table 3

Primary Diagnosis and Cause of Injury to Index Child as a Percentage of the Sample

Characteristic	Frequency	%
Primary Diagnosis of Index Child		
Spinal Cord Injury	1	16.66
Multiple Orthopedic Injuries	2	33.33
Traumatic Brain Injury	3	50.00
Primary Cause of Injury		
Bow & Arrow Incident	1	16.66
Dirt-bike Riding Incident	1	16.66
Horseback Riding Incident	1	16.66
Viral Meningitis	1	16.66
Motor Vehicle Accident, passenger	2	33.33

Gaining Entry

The 7 school-age sibling informants and their families taking part in this study were recruited for participation in the study at a pediatric rehabilitation hospital located in the Northeastern United States. The administration and staff at this organization are committed to supporting research projects to improve the health and care of children. The rehabilitation hospital offers a wide variety of both in-patient and outpatient rehabilitative services to medically complex children and their families, and as such, was a fruitful environment in which to recruit participants. In 2007, the hospital treated 96 children for Traumatic Brain Injury, 14 children for Spinal Cord Injury, and 84 children for other General Rehabilitation diagnoses (K. DeWitt, personal communication, April 4, 2008).

As a former employee of the hospital, many key leaders in the organization were known to the researcher. After meeting with a few members of the senior leadership team of the hospital to present and explain the research study, the Vice President of Patient Care Services granted the initial approval for this research to be conducted at the site in accordance with the approval of the Seton Hall University Institutional Review Board (IRB).

Over the course of 13 months, the setting provided opportunities to successfully recruit a sufficient number of school age siblings of traumatically injured children into the study. During this timeframe, the mother or father of every sibling who fit the criteria for inclusion as a research participant was approached by a nurse manager at the site and invited to participate in the study. Only one family declined to participate in the study.

Based on his knowledge of the families, the hospitalized child's diagnoses, and the family composition, one of the nurse managers at the hospital hand delivered recruitment letters only to appropriate families fitting the criteria. If these potential families were interested in learning more about the research, they filled out a form which was left in a secure locked box on the unit. After receiving these forms, the researcher contacted the parents to set up a time and place at the hospital to discuss the details of the study. If the parents consented to allow their school-age sibling to participate in the study, the researcher then spoke directly to the potential sibling participant to explain the study and seek the sibling's assent. Every sibling with

whom the researcher spoke about the study willingly accepted the invitation to participate.

Data Collection

Data were collected through interviews with the research participants. The interviews were semi-structured, individual conversations with the school-age siblings, conducted by the researcher. The siblings spoke for themselves, using their own words, based on their own perspective and perceptions. Only the researcher and the sibling informants were present at the private interviews. All interviews were conducted in a private conference room or office at the hospital. Most interviews were conducted in the late afternoon or early evening hours when the school-age sibling arrived at the hospital after his or her school day.

Each interview was audio-recorded on a small digital recorder, positioned inconspicuously in the room. Code numbers were assigned to each interview and announced at the beginning of each recording. No real names were used. Interviews ranged in length from 25 to 58 minutes, and were transcribed verbatim as a word document.

Overall, data collection proceeded without problem or incident. Privacy during the interviews was never breached, nor did any of the siblings have a serious or upsetting reaction during the interview. Indeed, all of the siblings showed a favorable response to the interviews and many displayed noticeable enthusiasm, as

shown when one sibling spontaneously hugged the researcher and said, "Can we talk again?!"

Data Analysis

Phenomenology seeks to describe, identify and understand basic psychological processes operating within the conscious experience of human beings as revealed by the actual people living the experience. It seeks to explore the experience of a phenomenon by allowing the essential meaning of the phenomenon to be discovered in the data and to be revealed as themes (Munhall, 1994, 2007; Van Manen, 1990). To accomplish these aims, data must be analyzed in a way that themes are identified and the meaning of the phenomenon is derived.

The written transcriptions of the interviews were read and re-read so that patterns and themes common to the experience of the school-age siblings became manifest. Much time was spent reflecting upon the data, which allowed for "dwelling" with the data (Munhall, 2007, p. 179) in such a way that a deeper understanding of the meaning of the experience was, indeed, uncovered.

Selective words and phrases in the transcriptions, that is, the spoken words of the siblings, were labeled and coded using the traditional techniques described by Ely (1991, pp. 87-89). Categories were developed; labels, codes and categories were then linked and sorted as the primary level of extraction; patterns were identified and themes were discovered as they revealed themselves. Finally, in a higher level of extraction, metathemes emerged. This process was not linear, but rather it was cyclical. It involved continuously going back to the transcriptions and re-reading the

words of the siblings as thematic identification and development was occurring. Four major themes regarding the phenomenon were identified with many subthemes, and ultimately 3 over-arching metathemes emerged.

When providing evidence of themes revealed in the data, Munhall (2007) cautions phenomenologists not to be reductionistic and to always "write inclusively of all meanings, not just the 'general' but the 'particular'" (p. 200). Therefore, independent themes discovered in the data of individual siblings, not found to be redundant or repetitious in the data, are still indeed significant in meaning and were included in the findings of this study.

Data analysis also included a search for similar or related perspectives on the phenomenon found in art and literature. Van Manen stated that, "literature, poetry, or other story forms serve as a fountain of experiences to which the phenomenologist may turn to increase practical insights" (1990, p. 70). Therefore, to enhance the analysis, a search was conducted for examples of the themes in children's literature, music, art, film and other sources. Many interesting examples of these were found in a variety of sources, especially on *sibling relationships* in children. Due to the information explosion occurring in the 21st century, and with children increasingly utilizing and connecting to the World Wide Web, many child-focused and age-appropriate internet resources were found that added insight to the phenomenon.

Chapter IV

FINDINGS

Vignettes

Each sibling's story has been précised into a small vignette, designed to impart a sense of individuality and wholeness to the reader regarding each sibling informant. Although these 7 school-age siblings shared the same phenomenon of interest, and had many common threads to their experience, each sibling shared his or her own unique story which should not be lost. All names, of course, are fictitious.

Sam.

My name is Sam and I am 9 years old. I have 2 older sisters. My 13 year old sister is in the hospital because she hurt her head. She was in a coma for about a week before she woke up, and now she is trying to get better. They say her brain is damaged. She goes to therapy everyday and they are teaching her how to walk and talk all over again. When Leah was first hurt in the accident, it was fun for me. I got to spend every day after school at my friend's house. I even slept over there for a while. But soon my uncle and grandparents came to help. Things changed. My parents were always at the hospital. I didn't see them all the time like I usually did. My Dad couldn't even come to all my football games like he use to, but he tried to come and see me play as much as possible. My Mom was not around much either. She was not at home after school when I got home. I miss my parents. It's hard not being with my mom or dad, because I am not use to that. I want them to see that me

and my other sister are here, too. I want to tell them, "We're here too. Don't forget us."

Carrie.

My name is Carrie and I am 11 years old. My big sister, Leah, is 2 years older than me. We have a younger brother, too. I am right in the middle. Leah is in the hospital because she has a bad fall and injured her head. Her brain was hurt and now she isn't the same. She is in rehab getting therapy to get better. They don't always tell me exactly what's going on with my sister, but I want to know! The first time I saw her after the accident she was in the hospital bed. It was weird. I never saw her like that before. I wasn't scared because I knew she was going to be OK, but I wondered, "How did this happen?" She slept for a week. And now she is doing much better. She is learning to eat and talk and walk again. My brother and I kind of got pushed from house to house. We spend a lot of time at our friends' houses. When I come to visit Leah at the hospital, she always got so many presents! And clothes, too. Everybody brings her things. I didn't get any--except for 2 bananas and a card. Sam and I would look at the piles of presents. She got candy, too. She got all the stuff. Then my brother and I would look at each other and say "Wow!"

Jackie.

My name is Jackie and I am 11 years old. I am starting middle school in a few weeks. I am the big sister of three girls. Four months ago my 9 year old sister and I were in a car accident. I got better real fast, but Jenny was very hurt. She is in a rehab hospital trying to get better. She broke her spine and now she can't walk. She cannot

go to the bathroom in the usual way. She wears a bag to collect her pooh and another one to collect her pee. It hurts me to see her this way and to see her in a wheelchair. It makes me very sad to see her problems. Sometimes I wish it were me and not her who was so hurt. When I am at the hospital I see other kids who were injured, too. I feel so bad inside my heart. It has been very hard on my Mom and Dad. I try to help out at home as much as possible, like cleaning the bathroom and tidying up. Mom is good at caring for Jenny. She knows how to put her tubes in and out and how to change them. My Grandpa and Dad are fixing our house so Jenny can come home real soon. They are building a new doorway to enter the house with a ramp and changing our game room into a bedroom for Jenny. It is very hard to see Jenny like this and not to have Jenny at home. I miss her being there. Before the accident we would argue all the time, but now I just want to be with her. I love her.

Courtney.

My name is Courtney and I am 10 years old. I have an older sister who is 17 years old and 2 older brothers. I am the youngest. A few months ago my sister was in a car accident. Someone else was driving and the car flipped over. She had lots of injuries. They took her to hospital in a helicopter. My sister doesn't even remember that part. She went to the Surgical Trauma Unit where she stayed for weeks. She had many operations and skin grafts. Now she is here in rehab trying to walk. She has been in a wheelchair since the accident, but the Physical Therapist has her up on crutches with a leg brace and walking a few steps. When she was first hurt at the hospital I was scared to see her. But when I did, it was OK. It wasn't as bad as I

thought it would be. Now I get to visit her often and she comes home on day trips for a few hours. I love when she comes home. I never want her to go back. When she is home we get to talk and talk. I wish she could stay home even for just one night. I want her to sleep with me. We share a room. I always complain when she has to go back. The hardest thing for me is when she is not at home. The house seems different when she is not there. My mom spends a lot of time at the hospital. My brothers are supposed to wake me up each morning and help me get ready for school. But I have to wake myself up. I set the alarm. I get up and get myself breakfast. Then I have to wake my brothers up! I get one of them to walk me to the bus stop because my Mom would want them to.

Wendy.

My name is Wendy and I am 12 years old. I am going into the 8th grade. I have a little sister, age 9, and a little brother. We live with our mother and father, grandmother and grandfather, aunts, uncles and cousins—all in one house. Last month my little sister got sick. She ran a high fever and started throwing up. She had a bad headache, too. She got very sick and has been in the hospital for almost 2 months, now. She has an infection in her brain. When I first went to the hospital to see my sister I didn't like it at all. I started crying because I had never seen her that way. I could not imagine the pain she was in. She had all this stuff in her arms. It was so hard. I said to myself, "This isn't the girl that I am always fighting with." It drew me closer to her. Before that, we were fighting all the time. Usually, I really don't like

her. But after that, I didn't want to fight anymore. I really like coming here. Now my sister wants to see me every day.

Michael.

My name is Michael and I am 11 ½ years old. I will be 12 next month. I have an older sister and an older brother, Patrick, who is 18. We all live together with my Mom and Dad. Patrick had an accident when he was riding his dirt-bike. He broke both of his knee caps--shattered them, but his head was OK. They had to medi-vac him to the Trauma Center. When I first saw Patrick at the hospital I was sad, but it was OK because I knew he was a strong guy and he could face it. Right now my mom is really busy trying to make arrangements for Patrick to start school. He is starting college soon, and mom is getting him into a special dorm. I am trying to help more around the house. I set the table, clear the table, feed the dog and do more of the little stuff. I kind of like helping out more. I still get to hang out with my friends, but not as much since Patrick's accident. I spend more time talking with Patrick now than before his accident. I think our relationship is getting better because we talk a lot more. He tells me about how he is doing and what's going on with his therapy. When I am at the hospital I listen whenever the nurses are talking to him, and I sneak a peek at the computer screen. That's how I get my information. Yesterday I came in and Patrick was on FACEBOOK. It made me happy because this is something he usually does. He was talking to his friends. That's a good thing. It made me happy.

Brittany.

My name is Brittany. My sister and I are twins, 8 years old. We live with our Mom and Dad. Me and Beth were playing with our friend in his backyard and a toy hit my sister in the head. She collapsed and was rushed to the hospital. Now she can't walk or talk or eat right. After she got to the hospital I didn't see her for a long time. They allowed me in but I didn't want to go see her. I just wasn't ready to see her. I stayed with my grandmother. After a month I did go in and see my sister. Now I come and see her every day. My Dad picks me up from school and we come straight here. I do my homework here. I am always here. At home, me and Beth share a room. But she is not there now. I am not use to that. So now I sleep in with my Dad. Dad sometimes takes me to school now, because before she was hurt, Beth and I would take the bus to school together. Now I have to go to school by myself.

Themes

Four major themes (see Figure 4.1), and various corresponding subthemes encompassed within each theme (see Appendix B), were discovered in the data. The 4 major themes, which encompassed some overlapping elements, were:

- Compassion
- A Difficult Experience
- Changes
- Constants

Figure 4.1. Major Themes

Compassion.

Compassion was the first major theme to emerge from the data. The school age siblings participating in this study showed a depth of compassion for their injured brothers or sisters, as well as for their parents and other children at the hospital. *Compassion* was the strongest and most common theme revealed in the analysis of the data, and was composed of several elements or subthemes: *sadness, empathy,* and *altruism.*

Sadness.

Sadness was expressed frequently by the siblings throughout the interviews and described in terms of how the siblings *felt* when seeing their injured brother or sister. Referring to her sister, one sibling explained that the saddest and hardest thing for her was "her things, her pain. Stuff like that. Her problems. I feel sad, 'cause I

don't really like when she's in pain. I feel, I start crying with her because I don't like when she is in pain."

Siblings spoke about how sad they felt especially when they saw their brother or sister for the first time after the occurrence of the traumatic injury. This initial experience was difficult for the siblings. One sibling stated, "In the beginning, it was kind of sad," and "Sometimes when I go to visit her, I get sadder." When speaking about the hardest and saddest thing for her, another sibling explained that it was sad "when I found out she was in the hospital." Another sibling told of his experience seeing his brother for the first time after the accident and realizing that he was in pain: "It was kind of sad. He doesn't like that I know it will hurt a lot. It was kind of sad because that day they took him off his medication . . . he started screaming and stuff."

Siblings expressed sadness at seeing children at the hospital, that is, patients other than their brothers or sisters, who were also injured and/or physically compromised. Frequently they encountered these patients on the clinical unit, in the various therapy areas, and in the recreation rooms. One sibling communicated her sadness by stating, "I feel sometimes sad. When I'm in the hospital I see people. There's a type of wheelchair they use. [Referring to a motorized wheelchair.] I feel so bad inside my heart. I feel bad 'cause I wish this never happened to them. And I wish that they felt fine, and walked, and do their things."

Sadness became profound at times and was expressed as a deeper feeling. For example, "One little boy, who can't talk, they made a type of chair for him so that he does everything himself. He drives the chair by himself. And I feel so bad for him

because he can't move his hands. His hands are like this [indicating contracted flexion in the hands and wrists]. I feel like, bad. I feel sad. I feel I want to cry." And further, "And some kids, they were in a bad car accident. I feel bad for them, because they were more hurt, just like my sister." She continued, "I feel sad. I feel uncomfortable. I feel like, I wish I was them, and they were me." Further, "I feel uncomfortable when people are really injured. I feel really sad." She continued, "I hoped, I wished, that this never happened, because this is the worst thing ever."

Empathy.

Sadness advanced to *empathy* for one sibling. She described one of her first experiences with her sister after the accident: "Me and my sister, we started crying, because she had a bunch of things that I wish didn't happen to her. I kept telling her, 'I wish it was me and not you.'" Another sibling expressed *empathy* for his brother when he stated, "I want him to have whatever he wants, because he is here." And further, "I don't want to hear my brother crying." Conversely, when his brother was happy and enjoying something, like getting back onto FACEBOOK, connecting and communicating with friends in his usual way, the sibling became "kind of happy about that."

Altruism.

Compassion reaches a level of *altruism* for one particular sibling. When talking about when she visited her sister at the hospital, she expressed how she wanted to help her sister: "It's hard for me and her. Because sometimes I start crying. I just want to be with her. I want to help her. I start crying because I wish I was an

adult already so I could be with her—help her—with things. Her things, that she doesn't feel comfortable with. Like with things that hurt her the most." The sibling became introspective when she stated, "I want to help her, but I am still a girl."

A difficult experience.

Another major theme was *a difficult experience*. Many siblings described their experiences as *hard or difficult*, with different things about the experience contributing to the difficulty. The subthemes encompassed within *a difficult experience* are: seeing the injured child, pain, and loss.

Seeing the injured child.

The first time seeing their brother or sister after the occurrence of the accident was typically described as a "hard experience" by the siblings, whether this experience took place in the acute care hospital or at a later time in the rehabilitation hospital. The intensity of the moment moved some of them to react strongly. For example, one sibling told about when her sister was first hospitalized, "I visited her. I started crying because I never saw her that way." She continued, "When I saw her, I started crying. When I saw her, it was like she had all this stuff in her arm, tubes in her arms."

One sibling was hesitant to see her sister for the first time after the accident. She described, "It was kind of creepy seeing her. So I didn't really go in. It was weird. I never seen her kind of like that." Another sibling even delayed her first encounter with her sister after the accident. She explained, "Well, they allowed me in.

But I didn't want to go see her. I just needed—I just wasn't ready to go see her." In fact, she did not choose to see her sister until a few weeks post-accident.

Another sibling compared the way she first saw her sister to her sister's condition weeks later, commenting on the visible equipment and altered appearance: "I saw her when she was in the Critical Care unit. I saw her when she was there and, like, she didn't look as good [as now] because she had a lot of stuff on her. She couldn't really get out of bed. She had, like, swollen fingers from the fluids they put in her." These visual images were described with negative verbal expressions by the sibling. Another sibling related that the hardest thing, "was probably looking at the G-tube, because she has a G-tube here and every time I see it, like, I get grossed out. Sometimes I get scared of it."

Pain.

Particularly difficult for siblings was when they witnessed their brother or sister in pain. Many siblings commented on this experience. For example, one sibling described when her sister was experiencing wound care: "She started to get nerve sensation. She was able to feel when the air touches it [the exposed wound]. Like, I would not want to have to be there and watch her. I heard she cries and stuff."

Another sibling declared that when her sister was being subjected to a medical procedure, it was hard for her to be there and see it done. "One time I saw them do the thing, it was like 'ouch.' I can't imagine the pain she actually is in." Similarly, another sibling explained that he did not like to watch procedures being done on his brother or treatments that caused his brother pain. His response was to leave the room

during procedures: "I don't want to watch, like, something that will hurt him. I might go to a different room for a couple of minutes."

Loss.

An element of this experience contributing to making it a "hard" and difficult event for the sibling was a *sense of loss* of parental contact. Siblings frequently spoke about missing their parents and not seeing them enough during the experience. In effect, the parents were *not there* for the siblings in the same way to which the siblings were accustomed.

One sibling was accustomed to having both his parents at his sports activities, but that changed when his sister became traumatically injured. He related, "Dad always took me to football practice, but when Leah got hurt, my friends' parents took me." He explained that the hardest thing for him in this experience was "being left alone. Not really alone, but not being with mom or dad as much. That was hard, because I wasn't use to that." Another sibling explained how she and her younger (non-injured) sibling would "act up" when they would finally see her mother. She said, "When we would see our mom, it was later that day. And we would kind of act up, 'cause we really hadn't seen her for a while. She was always there, at the hospital." She further explained that the hardest things for her were a change in routines and not seeing her parents on a regular basis: "[the hardest thing was] not being home every day for dinner and stuff, and, I want to see my dad everyday and my mom every day. I couldn't see my mom or dad one day, because I had to be with my grandma and grandpa."

Another sibling described her need to spend time with her mother: "Sometimes my mom and dad switched, because we wanted to spend time with my mom." Additionally, she wanted to spend more time with her mom and injured sister: "I want to spend time with my mom and sister. I want to spend more time with my mom. I just want to be with my mom. Be with them. Talk with them. Be closer to them."

Another sibling verbalized that the hardest part of this experience for her was "not having my sister at home." Still another sibling said, "the hardest thing is not being with her [injured sister]; not being with her; not supporting her." She explained that she was use to being with her sister everyday. Another sibling said that the hardest thing was "not seeing my sister."

Changes.

The third major theme revealed in the data was *changes*. The sibling informants participating in this study spoke about *changes* in their lives since the day that the traumatic injury occurred. This theme incorporated the subthemes of: *change in the sibling relationship, involvement of other caring adults, sleep patterns, daily routines,* and *other differences.*

Change in the sibling relationship.

The most significant change acknowledged by siblings was the *change in the sibling relationship.* At some point in the overall experience, siblings seemed to realize that they did, in fact, love their brother or sister. Talking about her sister, one sibling said, "She loves me so much, she's like, she always wants to be with me. She

always wants to play with me. I always want to be with her." She explained, "I always think about my sister." Another sibling explained the complicated relationship she has with her younger sister, which is typified by much fighting. She spoke about past fighting with her sister, and explained, "My sister would get mad at me and she will just hit me and then I get mad. Usually, I don't really like her." However, because of this traumatic injury and experience, she seemed to get emotionally closer to her sister, explaining: "When I saw her, I was like, this isn't the girl I kept fighting with. It kind of drew me close to love her." She further explained: "I like coming here because my sister usually doesn't like looking at me. But now, she forgets about the stuff we use to fight about."

When asked if anything has changed about their relationship, another sibling confirmed that he and his brother seem to have a better relationship now. He said that they usually fought "half-and-half" of the time they were together, but now "I think it's getting better, because we talk a lot more." He said that he "hangs out" now with his brother and plays games like ping-pong with him in the recreation area, and seems to enjoy being with his brother now.

Previous conflicts and attitudes may change between the sibling and affected child. For example, one sibling stated: "And now that the accident happened, everything is different. Everything's different. We have to take care of one another. And stop fighting with one another." This statement demonstrated a sense of responsibility and sense of family, which is reflective of a more meaningful sibling relationship and deepened sense of maturity in this sibling. She was further drawn to

consider the sibling relationship between her affected sister and yet another, younger sister. She wanted their relationship to improve, as well, stating: "My sister and Jenny can't stop fighting. They're non-stop fighting. I want them to stop, because they miss each other. I want them to get to know each other, to play with each other, get along better."

The experience of the traumatic injury and its consequences commonly made school-age siblings realize that they have strong feelings of affection for their brother or sister. This realization often lead to siblings acting differently toward their brother or sister and having a change in behavior. The sibling relationship can actually improve. For example, when one sibling spoke about her relationship with her older sister, a typical sibling rivalry was displayed when she explained: "We're really close in age and I would take her clothes and she would take my clothes. And we each tell each other we're ugly and fat, and all that kind of stuff." Paradoxically, she then commented on the change in their relationship since the accident and hospitalization occurred: "We kind of made up, cause it's kinda of lonely up there [in our bedroom] now."

Even with the realization of new found affection for the affected child, siblings still continued to experience previously established *sibling rivalry* (a constant). These old emotions and feelings did not become extinguished in the light of the current crisis, but appeared to be deeply rooted. At times, siblings talked about these normal feelings of sibling rivalry during the interviews. One sibling expressed her feelings toward her affected sister as she said, "At the rehab place, she got lots of

clothes. She got so many presents! She got so much clothes, and I don't. She got her presents, and I don't have any. I only got 2 bananas and a card." Small resentments and jealousies were still laced into affectionate relationships. This same sibling further explained the difficulty in seeing her sister get attention and gifts. She spoke about when she and her younger brother visited her affected sister at the hospital: "We go there and see groups of presents, full, and we keep looking at each other, and, say like—wow! She got all this stuff!" Additionally, when speaking about the bedroom she shared with her sister, she made a comparison of their two beds: "She's got a big bed and I have a small bed!"

Involvement of other caring adults.

Another noteworthy change that is part of the overall experience for siblings was the increase in the *involvement of other caring adults* in their lives. Many times it was the grandparents who provided the extra help needed during the crisis by providing care for the siblings, staying in the home, babysitting, and generally tending to the daily needs of the family and children. School-age siblings spent more time with their grandparents than usual, especially during the initial phases of the crisis. For example, one sibling related, "My mom use to help me, but then my grandma came and she helped me in the morning instead. My grandma started to come on Tuesdays, Wednesdays, and Thursdays." Another sibling ended up staying at her grandparents' house in a nearby town for a month when her sister was injured. She explained, "I slept over their house for a month." Also, her other grandmother traveled from a European country to the United States after the accident happened

specifically to see the injured child and provide care for the school-age sibling. This sibling remarked that having her grandmother from another country live with her was something "different" for her.

When first meeting with one family who was interested in participating in this study, the mother arrived at the hospital with her 2 other children and was accompanied by the grandfather. It quickly became apparent that this grandfather was very involved with the family and was a source of help and support to the family throughout the current crisis. The school-age sibling explained that even while she and her younger sister visited at the hospital, they were never left alone. Grandparents were always there for them. When she was told to leave the hospital room by her mother because special care was being rendered to the affected child, she stated, "Usually my grandma stays inside [the curtain surrounding the bed] and helps my mom and my dad. And me and my grandpa and the little one just stay outside. We are never left alone, 'cause I know some kids are." Or sometimes, "we'd stay there and watch TV with my grandma and grandpa." And when the family was at home, the grandfather was present to help them as well. The sibling affirmed the helping presence of the grandparents: "And my grandpa keeps saying, 'I'll do it. I'll do it.' 'Cause my grandpa wants to help my mom."

In addition to grandparents, other extended family members were sometimes involved with helping out the family and spent time caring for the siblings. For example, one sibling spoke about the first few weeks after the accident: "My uncle and grandparents would take us sometimes. That was OK." Similarly, another sibling

told, "Once we slept over at my uncle's house, which was actually not that bad, because we have all these cousins there, and so we went to 6 Flags [Amusement Park]." In the same way, friends and the parents of friends were involved in supporting the siblings early in the experience, as another sibling explained: "I stayed over at my friend's house that night [when my sister was injured in the accident], because my parents slept up at the hospital." Likewise, another sibling told about going to friends houses' when he said he went to "this one's house or that one's house. And I wasn't home much. I didn't go home after school. That lasted for a while." He further explained that his other sibling went to her friend's house after school in the days immediately after the accident, "While Dad and Mom were at the hospital with Leah, Carrie was at her friend's house." Later, she stated, "My brother and I got pushed around from house to house—kind of—sort of. Friends' houses. Sometimes we go to our uncle's." She explained that when her parents were visiting at the hospital, "we are at grandma's, at our uncle's, at a lot of friends' houses. Because we have totally different friends, I would go to my friends' and he would go to his friends' and we would just meet at the end of the day."

Sleep patterns.

A strong subtheme that emerged from the data was the changes in *sleep patterns* and habits experienced by several of the school-age siblings. Many things associated with sleeping and sleeping arrangements changed for the siblings. At times this change was in the actual bed or bedroom, and involved a change from sharing a bedroom with another person, such as the injured child, to being alone in the room at

night while sleeping. Sometimes this lead to unsettled feelings about the new sleeping arrangements, which in turn lead to the sibling sleeping in the room or bed with the parents. Sometimes it lead to the sibling seeking out another comforting place to sleep. Siblings exhibited these changes in sleep patterns and habits in different ways, but spoke about this subtheme freely. The youngest sibling participating in this study, who ordinarily shared a bedroom with her sister, stated that the "biggest difference" in the entire experience for her was her new sleeping arrangement. She commented, "I don't sleep in my bed. I sleep in another room with my dad. Sometimes I sleep in his bed over the weekends, like when I fall asleep while watching a movie." She explained that she was accustomed to having her sister in the room with her, but since the accident and hospitalization of her sister, this sibling slept with her dad because she did not want to be alone in her own room. She said, "because I am not use to it." Another sibling agreed that changes in the sleeping arrangements were the "biggest difference" she encountered in the experience. She related:

> For me, the biggest difference is that my sister and I usually share a room when my brother, Josh, is home, because that is when I get his room—when he is away. So, that's kind of different for me because me and my sister shared a room. We always shared a room until Josh left to go to college. It's kind of different even though my sister and I have had separate rooms for a long time. I am use to when Josh is home, I share a room with her, so that is kind of different.

And, moreover, this sibling said, "I want to sleep with her."

Another sibling, unable to sleep in the same room with her sister during the hospitalization, explained that, "It's kind of lonely up there. I'm back sleeping in her bed. I sleep in her bed." Sleeping in her sister's bed seemed to be a comfort and consolation to the sibling.

Another sibling, although she did not share a bedroom with her sibling, explained that there were plans to change and update her bedroom. Prior to the accident she had an adjacent bedroom to the injured sister, and the two frequently visited each other in one another's rooms. But since the affected child would then be sleeping in a new room being converted on the first floor of the house, the sibling explained that, "Now they're going to change my room. I'm going to switch my bed, and the colors, too. And she's going to spend time with me and my sister upstairs, 'cause we usually go upstairs, not downstairs." It was the sibling's perception that her own bedroom was being modified purposely since her injured sister would spend leisure time with her in her bedroom, not sleeping, but "visiting."

Another sibling explained that he normally shared a room with his injured brother, but since that brother would be in a wheelchair for a while, sleeping arrangements were changing and they no longer would share a room. He said, "We have a guest room. I think we are going to rearrange my room because I think he is going to the guest room."

Daily routines.

Aside from changes in sleep patterns and sleeping arrangements, there were other changes in *daily routines* which siblings typically experienced in their daily

lives. These changes were described as "difficult" by some siblings. One sibling recounted what was most difficult about the entire experience as "not being home every day for, like, dinner and stuff."

Sometimes, it was the usual early morning routines of the siblings which changed. One sibling explained, "My routine before school was different because my mom use to wake me up. My mom use to, just like, help me in the morning." Her mom was not there in the mornings anymore and other family members helped this sibling with her morning routine. When it was her older brothers who helped her, she revealed that:

> My brothers aren't the best at waking me up for school, so I usually have to wake myself up with an alarm. I have to wake them up. I sort of got use to waking myself up. So I get myself up, get myself some breakfast, wake up my brothers, and tell them I have to be ready for the bus soon. And, I need someone to walk me down to my bus stop. Because my mom usually likes someone to walk me down to my bus stop.

Other siblings also spoke about changes in their morning routines. One sibling usually took the bus to school along with her affected sister, since they attended the same school. But since the accident occurred, this sibling traveled alone on the bus. She explained, "We'd sit at the same seat." After the accident occurred, she then took the bus and sat on the bus with her "neighbor." She explained that not having her sister there with her on the bus was hard for her. She said, "I usually get use to her being next to me." Another sibling was also accustomed to traveling to school on the

bus with her sister, but that changed. She shared: "Sometimes I go on the bus [alone]; sometimes my mom or my dad brings me [to school]." Hesitantly, she commented about this change in routine, saying "it's OK." This same sibling was picked up after school by her father and brought to the hospital every day. At the time of the interview she was spending most of her after-school time at the hospital with her parents and sister. But for another sibling, the opposite was true. Her usual pre-accident routine was to spend much of her time on weekdays with her older, affected sister, especially since the mom worked full time and the older sister was left in charge of the sibling. She explained, "On the week days, I am usually with my sister." Since the hospitalization, she has not been able to spend as much time with her sister.

The dependence of school-age siblings on other adults throughout this experience was evident in the comment stated by one sibling, as she explained that the availability of her father and older brothers to drive her to the hospital influenced the amount of time she was able to spend at the hospital with her sister. After school, she wanted to go to the hospital to see her sister, but the amount of time she was able to spend at the hospital with her sister changed depending upon who drove her to the hospital. She said, "My dad would come home, like we would have to clean the house up a bit, and then we come here [at the hospital]. And then I would get to spend 5 minutes with my sister, and then we go. Now I get to spend more time with my sister because my brothers will drive me up [here] and it is easier for them."

Another change in daily routines that emerged for siblings was an increase in the household chores and tasks that they assumed. One sibling shared, "When my

mom and dad are working, I usually clean the house with my [other] sister. I clean the bathroom and everything. And they help me. We have fun." Similarly, another sibling talked about the chores he took on, as he said:

> I am starting to have more to do—a lot more stuff around the house. Usually I set the table. So I do that, but then since my mom goes to the hospital a lot, I have to set the table, clear the table, feed the dog, and more of the little stuff.

He explained how these additional chores have changed his usual routine. He said, "I use to spend my days, like, kinda relaxing and seeing what my friends could do so I can, like, hang with them. But now, I kind of like helping out more."

Other differences.

When asked about changes in their lives since their brother or sister incurred a traumatic injury, several siblings were able to identify something specific about the experience that they referred to as *the biggest difference* for them. All of the examples talked about by the siblings centered upon less contact and less time spent with the injured child.

One sibling spoke about the decreased amount of time she now spends with her sister. Usually, this sibling spent a lot of time on weekdays in the company of her sister, even though they are 3 years apart in age. These activities included time together traveling back and forth to school, after school activities in the home, and some select activities such as play dates and sleepovers with her sister and both sets of their friends. Interestingly, this sibling lived with an extended family of 3 generations including grandparents, aunts, uncles and cousins. Since this sibling

described her sister as "talkative" pre-injury, the sibling might have been extraordinarily aware of the decrease in time spent with her sister when it became diminished.

Similarly, another sibling spoke of the biggest difference for her being the new arrangement of not sharing a room anymore with her sister. She said, "For me, the biggest thing that is different, my sister and I usually share a room. We always shared a room. It's kind of different."

Another sibling said that the biggest difference for her was the change in sleeping arrangements following her sister's injury. This sibling shared a room with her twin sister and now was afraid to stay in a room at night by herself. Post-accident, she was sleeping in the room with her father, as she explained, "I don't sleep in my bed."

Constants.

The fourth major theme was *constants*, the things which remained constant in the lives of these school-age children throughout the experience. This theme encompassed 2 subthemes: *school life*, and *having fun.*

School life.

A recurring subtheme became apparent: time spent at school *essentially stayed the same* with little change for the sibling. It was a constant in the experience. When asked about whether things at his school were any different, one sibling responded: "No. Not really. School is OK. It is not really any different. School is about the same." Similarly, another sibling said that seeing her friends again at school and

playing with her school friends was "back to normal." [At the time of this interview, the timeframe was 5 months post-accident for this family.] Still another sibling shared that, "School is mostly the same. My teachers sometimes let me do some homework in class, just to let me, so I can visit my sister immediately after school. But actually there wasn't much difference at all." After school activities and sports were the same for this sibling, too, as she told, "I went to my games and practices and everything. Yeah, I did most stuff normal." She also told that her family—mostly her father—was able to attend most of her after-school sports games and that aspect of her life remained basically unchanged: "My dad usually went. My cousins came sometimes just to give me support and stuff." None of the 7 siblings ever said there were differences or problems regarding school or school-related activities.

When an interview was scheduled with another sibling, the mother telephoned me a few hours before we were to meet and asked me to delay the appointment with the sibling. The reason given for the postponement was that the mother forgot about the sibling's Brownie-scout meeting that day, and she did not want the sibling to miss her meeting. The sibling was still attending her usual after-school activities—another constant in the experience.

Having fun.

For some of the sibling participants, the experience of having a brother or sister with a recent traumatic injury was initially *a fun experience* for them. Sometimes the fun arose from the opportunity to spend more time with friends, particularly at friends' houses. One sibling recounted, "At first it was kind of fun,

because I was going over my friend's house—staying with friends, especially after school." He continued, "At first I was playing with my friends all the time, while my mom and dad were at the hospital with my sister." Another sibling stated, "So I know some good things happened, just like, well, for me, I got to sleep at my friend's house on a school day. Yeah, it was fun for me."

At times, siblings made new friends at the hospital, as one sibling explained, "Sometimes I talked to some of the kids in the playroom. I'd get to play with some of them. It was fun." Similarly, another sibling said, "And, like, it was fun for us [the sibling and affected sister] because we got to interact with other kids, too." Still another sibling talked about the opportunity to make new friends at the hospital. "I made new friends at the hospital, at 2 hospitals [both the acute-care hospital and the rehabilitation hospital]." She continued:

> I was happy because I made new friends with the patients. I made friends. We talked together; we'd read things together; we'd play games. I felt happy about it, that they're not thinking about their injuries. They're thinking about having fun.

She also reflected, "They should have more fun, instead of, like, remembering their injuries. Having fun is more important. It is a good thing." She further explained:

> I think, they should like, not worry about injuries 'cause that's the worst part to think about, 'cause then you hurt, you feel pain, you feel sad, some mad, and um, they should stop worrying about the injury and pay attention and have fun. Have fun more.

The element of fun was not limited to spending more time with old and new friends; but rather, fun extended to participating in new and enjoyable activities. For example, some siblings spent time at the hospital participating in fun activities with their injured brother or sister. They played games with them, did art projects together, and attended organized therapy sessions, including physical therapy and recreational therapy. One sibling stated, "Sometimes when there is not much visitors, I am in the room with my sister, and then when she has the therapy and stuff, I go with her." One sibling spoke about the Recreation Room located on the clinical unit and explained the fun she had there with her sister: "We do stuff here actually like the Rec Room and we go there a lot together. And we will play ping pong together in that one room and so we have fun."

Another sibling explained what she did with her sister while visiting her at the hospital, "I'd start playing, eating, play games, talk to her. We'd visit, like, a few hours." She continued, "I'd talk to her. I'd play with her. We'd play games."

Although siblings frequently played with their brothers or sisters at the hospital and attended recreation therapy with them, when the affected child was not available or not able to attend recreation therapy, siblings still went themselves and participated in fun activities. One sibling proclaimed that she would go to Recreation Therapy with or without her sister. She said, "On Saturdays, I go to, like, therapy. Sometimes on Saturday I go there. If she is not feeling well, I go by myself." She explained that it is when she attended Recreation Therapy that she was able to make other friends at the hospital.

Another sibling explained that she attended Physical therapy with her sister, but sometimes she did not and preferred to go to the Recreation Room herself, where she could have fun. She shared:

> This place [the rehabilitation hospital] is more, you can like, 'cause they have the Rec Room, and that's where they have games and everything, and so it's fun. So even if my sister is in PT, and even though sometimes I go to her PTs I don't want to go sometimes, I'll just go to the Rec Room, and they have games from 6. Like sometimes they'll keep it open all day, but they always have one thing from 6:15 to 7:30, really, so I go.

When asked if going to recreation therapy was fun, the sibling replied, "Yeah." This sibling felt comfortable going to the Recreation room by herself, and said that "sometimes I would just go down to the Rec room without my sister. They don't care. They just allow me there." She agreed that she feels welcome there.

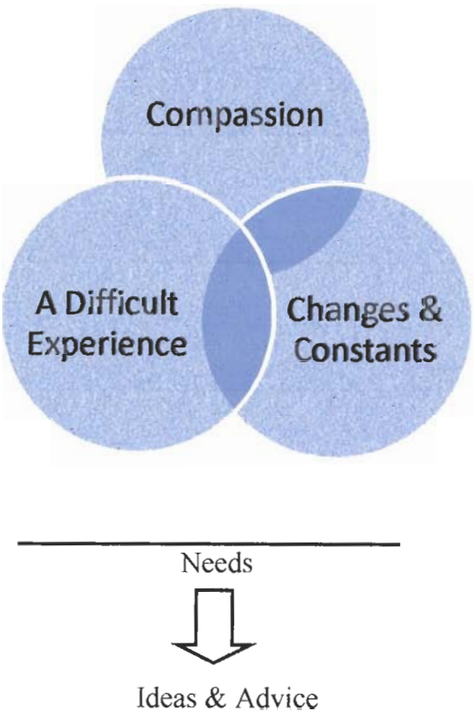
Another sibling explained that she had fun in the Recreation room, which her sister was still unable to visit. She declared that one of the best things at the hospital was "the ping pong table" as she really liked the game. This sibling played ping-pong frequently at the hospital with her father, greatly enjoying it. The game of ping-pong was also enjoyed by another sibling, whose brother was doing well and improving in his physical skills. This sibling went to Recreation with his brother at times or played there himself. He explained, "With my brother, yeah, I go there with him sometimes, and he will fall asleep, and I'll play ping-pong a little bit."

Another sibling found a way to help her sister by making her laugh during a difficult procedure, adding an element of fun. She explained that when her mother was performing colostomy care on her sister, "It hurts her, too. So I hold her hands, and just make her laugh."

Siblings Speaking Out

Siblings were asked if there was anything that they wanted adults to know. At times, siblings were able to identify and express their own needs related to the

Figure 4.2. Needs Development from Major Themes



experience, state advice they had for future siblings undergoing this phenomenon, and suggest ideas regarding how the needs of siblings could best be met by adults and health care professionals (see Appendix C). As depicted in Figure 2, the needs, advice, and ideas conveyed by the siblings were borne of the experience and derived from the four major themes.

Needs.

Several siblings participating in this study spoke about the need for *recognition and validation* of their identity and a confirmation of their own importance, apart from their brother or sister and the unfolding experience, and alluded to their frustration when they did not receive this validation. One sibling said, "I feel like I should be important, too, 'cause, usually my sister is, (pause) my mom and dad give her everything she wants. I should be important, too." She continued, "I should be part of it, like important. So, like, that's how I feel. Uncomfortable. 'Cause me and my [other] sister are left behind."

Another sibling expressed a similar point of view. When asked what he would tell grown-ups about the experience if he were given the chance, he succinctly replied without hesitation, "That we're there, too. Don't forget us." When another sibling was asked the same question, she replied just as swiftly, "It's just as hard for us as it is for them."

The siblings talked about not being recognized and personally greeted by the nurses on the clinical unit who were caring for their brother or sister, and how that related that to their need for *information and communication.* All 7 siblings gave

similar descriptions, stating that the nurses encountered at the hospital customarily ignored them. One sibling stated that the nurses "usually [spoke to] my parents and my sister. Usually they just tell my parents, and I just eavesdropped." Listening-in and overhearing discussions was the method this sibling used to get new information about what was happening with her sister.

Informational needs were highlighted by another sibling, as well. When this sibling first saw her injured sister, she wondered, "When is she going to be home? But, how did, how exactly did this happen?" This sibling wanted to know in detail what happened and to have physicians or nurses provide her with an explanation. She explained, "They didn't really ignore us, but they need to give us more detail." She recommended to physicians and nurses: "Maybe they can tell the sister or brother, like, what exactly happened. Tell us exactly what happened, and like, what is exactly wrong, and where and how."

Another sibling explained, "Some [nurses] would actually talk to me and tell me 'how was school?' and some would not. Some would walk by me. Some would say 'hi.'" She believed that, "Nurses and doctors, they only worry about the patient, and not the brothers or sisters." Referring to nurses, another sibling said, "Sometimes they will talk to me." However, this sibling used her mother as her primary source of information and not the healthcare professionals at the hospital.

Another sibling claimed that she was largely ignored by the nurses. When the nurses entered the patient room and she was present, "They pretty much go right to my sister." It was this sibling's perception that the nurses did not do "anything" with

her. Yet another sibling explained that when nurses entered the room, they never said anything to him, not even "hi." If this sibling wanted or needed information, he sought information in a unique way, explaining that "sometimes, they [the nurses] bring in this computer. Sometimes I stand behind and look at the computer because I know how to read that kind of stuff." Essentially, he looked over the shoulders of the nurses at the rolling computer-on-wheels to view information directly. "I would listen to what they were saying, or I would see what my brother says, because sometimes he would talk to me about it." He further explained that he wanted to be included in the information sharing and the decisions regarding care options for his brother. Speaking about nurses, he said, "They should know, like, how we feel, so they know how to treat everyone, like, better. So like, for example, like asking me or my sister [another sibling], my brother or my mom, or whoever, asking 'is it OK to do this, or should we do this for him?'"

Finally, another sibling spoke about seeing other children at the hospital who were hospitalized there and his inability to essentially understand or make sense out of what he observed. He related, "Well, when I went to the hospital, I'd see all the other kids there. And I didn't know what they were there for. I didn't know what was going on." He said no one spoke to him about this, yet he wondered about what he saw and had questions.

Advice.

One sibling offered advice to other siblings and their injured brothers or sisters who might live through a similar experience in the future: to *have fun*. She

suggested that they should not focus on the injury; rather, these children should deliberately try to "have more fun." She expressed a determination to remain positive throughout the experience, recommending: "Don't think about the injury—just [be] playing and playing." Although this sibling seemed to have a difficult time putting her thoughts into words, eventually she was able to explain more fully. She said, "They should have more fun, instead of like, remembering their injuries. Having fun is more important, a good thing." Expressing more detail, she continued, "I think they should not worry about injuries 'cause that's the worse part to think about. 'Cause then, you feel pain, you feel sad, some mad. They should stop worrying about the injury and pay attention to having more fun." This sibling found a bit of respite when she played with her injured sister at the hospital, as she related, "I'd talk to her, I'd play with her. We'd play games. It made me feel like this never happened. That's how it made me feel."

Another sibling felt that it was important for other siblings in similar situations to *know that "it is difficult* for brothers and sisters. [When] we're at the hospital, you feel sad. You feel different. And you feel like being with your sister every day. You want to be with your brother or sister more often."

Another sibling thought that other siblings in a similar situation "might want to go to the rec room or go watch TV" while their brother or sister was undergoing a painful procedure such as a dressing change or care of the wound vacuum, since it was "hard" to see your brother or sister in pain. In other words, siblings could *find other activities to do* during difficult situations with a brother or sister.

Some advice given by a sibling was directed toward nurses to *include siblings in activities*. She said, "I know the patients are there, but they [nurses] should do more with the brothers and sisters when they visit their sister or brother." She wanted to be included in activities with her sister, and believed that nurses should help orchestrate activities that they could do together. She believed that by doing more things together, the sibling and child would "learn more about each other."

Another sibling saw the value of a children's hospital and spoke of it as a good environment for children. She said, "I like it here because I am a kid. I am a child, so this is nice here for me." She explained that other families in similar situations should *consider using a children's hospital* since, "Sometimes this isn't the most positive thing, but at least this place is nice. This is a place for kids."

Ideas.

One of the siblings shared an original idea which is related to the sibling relationship. She suggested that an area be set aside on the clinical unit for the exclusive use of patients and their siblings. It would serve as a *Sibling Lounge* where brothers and sisters could spend leisure time together in fun activities, such as games, art projects, video-games, and movies. In her words, "They could have some programs here where brothers and sisters actually, could have, like, time where maybe they could have some place where, just maybe the two of them could hang out." She explained, "I know there is a Family Lounge, but maybe, just a Sibling Lounge. You could come with the person who is injured, so that everyone could hang out together."

Minor Themes

A few minor themes emerged which were not as strongly or frequently discussed by the siblings, but are still worthy of mention. A particular theme identified was related to the *role of protector,* assumed by one sibling for her older sister. This was the only sibling to speak so directly about protecting her sister, when she explained how the family's dogs might jump at her sister's injured leg. She said, "We are probably going to be a little more careful. Because we have 2 dogs, and sometimes they like to jump at legs . . . we will be more careful just to make sure they don't jump on her leg, because we don't want them to hurt her."

Another theme was related to *career choice*. One sibling declared that the overall experience of having a sister with a traumatic injury compelled her to consider a career in healthcare. She said, "When I was growing up I wanted to become an artist, but now that the car accident happened, I want to be a therapist or a nurse." Interestingly, this sibling was the very one that spoke about helping her mother with the physical care of her sister during catheterizations and colostomy care. She held her sister's hand during these procedures. She commented, "I help my mom. I am right beside her and help her do everything." This sibling's involvement in the care of her sister also demonstrated *inclusion in care*.

One sibling expressed her particular *need to talk* about the experience. Prior to this study, she felt as if no one wanted to speak to her about what the experience was like for her. She conveyed, "I felt like, people were like, no one wants to talk to me more, 'cause usually people are like, like, they'll want to talk to me usually about

everything, everything else in my life—everything else." At the end of our conversation, she expressed her desire to talk about the experience further. She said, "I hope we get together again. This was so much fun."

For another sibling there was a secondary benefit to the experience regarding *eating at the hospital*. This sibling liked the hospital food and was given a pass to eat at the hospital café. She claimed, "They had really good food. Sometimes I would just stop in and say 'hi' to my sister and then I'd go down and eat."

Even while her sister required very complex orthopedic care and therapy, one sibling maintained *a positive outlook* regarding her sister's prognosis and remained confident. She stated, "I knew she was 'gonna be OK." This sibling explained that once her sister left the acute care hospital and was transferred to the rehabilitation hospital, it became easier emotionally for her to see her sister. "It was so much easier to see her," she explained, "'cause I could see her up in a wheelchair and interacting with other kids and stuff." The sibling's positive outlook was revealed when she said she would tell other siblings: "[your brother or sister] is going to start getting better."

One sibling, who was only age 10 years, was *aware of* her sister's *care specifics and care requirements*. She understood and was knowledgeable about her sister's care, as she explained in specific detail:

> It is like, a sponge on top, and they are always changing it and everything. And then on this leg, there was something in her knee—I don't know what it was. And so in the beginning she had to keep this leg straight, and then, for a while, she just had the wound vac. Nothing on this leg. But then, when they

> did the skin graft, they took skin right off of right here—off her left leg and put it on right here on her right leg. So they took it from her left side and put it on her right side, and so she had to keep this leg immobilized for a while, I think, before. Yeah, when they put the staples in, and then, I forget when it was actually—a few days ago—they took the staples out and everything, and now she is starting to bend this leg again and walk on it.

This sibling said she was "comfortable" seeing her sister's injuries and explained that "because I want to be a doctor when I grow up, I think it's kind of interesting seeing some of my sister's cuts." It is remarkable to note that although this sibling was comfortable seeing her sister's extensive physical injuries, she later said that it was indeed "hard" for her to see her sister in pain.

Another sibling *helped with the care* of her sister. She talked about when her mother catheterized her sister: "I usually help my mom with her [sister's] things. I am right beside her. I help her do everything. I hold Jenny's hands. 'Cause sometimes, some things hurt."

There was just one sibling who thought that the great amount of time she spent at the hospital "was not so good." Although unavoidable by family circumstance, she said, "I am always in the hospital."

Chapter V

FINDING MEANING

Metathemes

"Metathemes are major constructs that highlight overarching issues in a study which may be considered against extant literature and experience" (Ely, Vinz, Downing, & Anzul, 1997, p. 206). Metathemes "are usually considered to be drawn from the entire body of data" (p. 206) in contrast to themes which are extracted from individual parts of the data. In doing further analysis of the entirety of the data of this study, 3 metathemes emerged: *An emotional experience* for the siblings, *an opportunity for growth* for the siblings, and *a different world* that now exists in which the siblings live.

An emotional experience.

The traumatic injury of a brother or sister was *an emotional experience* for well school-age siblings, and this emerged as a metatheme that encompassed several themes. Most of the siblings described their experiences of *sadness* and *empathy* with such detail and passion, that these feelings strongly contributed to this metatheme. The emotional nature of the experience was established when several siblings recounted how *hard* and difficult it was to see their brother or sister suffer in pain and undergo uncomfortable procedures. They spoke about *altruistic* feelings regarding their desire to help the children they saw at the hospital. Siblings spoke about their love for their brothers or sisters, and how much they loved them and wanted to be

with them. They missed them at home. At the same time, siblings spoke about feelings of sibling rivalry and jealousy which appeared to be an emotional conflict for the siblings. The sense of *loss* of parental contact and *loss* of the previous time spent with their injured brother or sister prior to the injury, reinforced the emotive nature of the experience. The siblings described their *need for validation and recognition*, and that they were still an important part of the family: "we are important, too." This life event is *an emotional experience* for a well sibling of a child with a traumatic injury.

Opportunity for growth.

Another metatheme of this study is: this experience is an *opportunity for growth* for well school-age children. A major theme of the phenomenon, *a difficult experience*, can often be transformative for any person living through the experience. Two elements of the difficult experience, the *difficulty in witnessing the pain* of their brother or sister and the *sense of loss* felt for their parents and the injured child, seem to have been triggers for the *compassion* felt by the siblings. Will this capacity for compassion develop more fully and become a part of the siblings' characters? Will this compassion add to personal and moral identification of the siblings? Although these questions are unanswerable at this time, the potential for emotional and social growth appears to exist. Additionally, *improvement in the sibling relationship* following the traumatic event, which several siblings spoke about, contains the potential for continued growth within the family system. The continued *opportunity for growth* of the sibling relationship was evident from the data.

The siblings in this study reported many *changes* encountered in their everyday lives related to the injury of their brother or sister, some of which may be long-lasting and/or permanent. Some of these changes will likely continue, such as new sleeping arrangements, newly assumed household duties and tasks, and increased independence with morning routines and readying themselves for school. Positive implications for growth and development of siblings seem plausible when viewed through the lens of Erikson's (1950/1963) developmental stages. According to Erikson, the child is developing a sense of industry vs. inferiority; the developmental task of this stage is to develop "method and competence" (p. 274). It is during this stage of development that the school age child first encounters "doing things beside and with others, a first division of labor" (p. 260). The opportunity to assume more accountability for themselves, and to contribute to the overall family duties and responsibilities, may foster siblings' competence and self-esteem in a valuable and positive way.

Erikson's (1950/1963) theory of development proposes that children develop competence through the successful accomplishment of tasks they attempt. When siblings were *included in the care* of the injured child, either by helping with the physical care of a brother or sister as one sibling described, or by helping to make decisions related to the care of the injured child as another sibling desired, the opportunity to develop a sense of competence regarding psychomotor and social skills was enhanced; thus, the *opportunity to grow* in self-confidence, as well as in

assumption of greater responsibilities within the family, can be considered part of the phenomenon.

A different world.

Although some aspects of their lives remained essentially unchanged, there were long-lasting and possibly permanent changes faced by the family (new and different demands for care of the injured child), the injured child (the functional disabilities of the injured child), and the sibling (such as a *change in the sibling relationship, changes in daily routines*, and *the need for recognition and validation*), in such a way that the experience may be described as *a different world* than the world that existed before the occurrence of the traumatic injury. Figuratively, the actual traumatic event became a pivot-point which changed the direction taken by the child, a type of water-shed event. It will always be a significant landmark in the family timeline, whereby all family events will be categorized as happening either "before" or "after" the traumatic event. Similar findings were suggested by Gill and Wells (2000), who studied adolescent and adult siblings of children with Traumatic Brain Injury. They found that siblings of TBI patients experienced qualitative re-patterning in their lives which lead to a sense of life being "forever different" (p. 49).

Support for Findings in the Literature

In an effort to further enhance the interpretation of the study findings, the literature was again reviewed.

Sadness.

Siblings experiencing *sadness* when a brother or sister was ill and/or hospitalized was supported in the literature. In an effort to understand more about children's feelings, *sympathy* as an emotional experience was studied by Szagun (1992). Structured interviews designed to elicit children's experiences of sympathy, and situations that educe sympathy, were conducted with 100 children. The ages of the children ranged from 5 to 15 years, and most were between the ages of 7 and 12 years. *Sadness* was the most frequently named feeling described by the participants which they identified with compassion; furthermore, the researcher's hypothesis that younger children would identify sympathy with *sadness* was confirmed. As the age of the children increased, other feelings were described as being identified with the experience of *sympathy*, or as the researcher phrased the question to the children, as part of "feeling sorry" (p. 1186). Findings showed that as the age of the child increased, other responses besides sadness were described as part of sympathy, that is " having a desire to help" (p. 1189), and "having preoccupied thoughts about the other in distress" (p. 1189). All three components of sympathy described by Szagun were described by siblings in the current study; they are *sadness*, *a desire to help*, and *thinking about the person (the brother or sister) in distress*.

Stress was found to be experienced by 77% of the healthy school-age siblings of children hospitalized with acute illnesses in Morrison's (1997) study. "Of all the siblings who experienced stress, a common factor was that of feelings of *sadness* during that time" (p. 27). Stress was observed to manifest as *sadness* in siblings who

were visiting their critically ill brothers or sisters in a Pediatric Intensive Care Unit (Rodilsky, 2005). Montgomery (2000) studied siblings of hospitalized children and found that the most frequent self-reported feeling experienced by 10 school-age siblings in her study was *sadness*. "I am sad because . . . I really miss my sister" (p. 118), was how one 9 year old female sibling in the study explained her sadness. Fleitas (2000) discovered that siblings of ill or disabled children experienced feelings which were reflective of stress; one of these feelings was categorized as sadness. All of these studies (Morrison, 1997; Rodilsky, 2005; Montgomery, 2000; Fleitas, 2000) confirmed and supported *sadness* as a major sub-theme found in this study.

Altruism.

The study subtheme of siblings having a sense of *altruism* toward their brothers or sisters, and sometimes toward other ill children they met at the hospital, was supported by one other research study. Fleitas (2000) reported, "Altruism is displayed by many siblings of children with complex medical needs" (p. 271). She labeled altruism as a "theme of resilience" (p. 270) shared by many siblings.

Sibling rivalry.

Siblings in this study experienced typical sibling rivalry and feelings of jealousy, as reported in other studies. Fleitas (2000) documented the same findings in the siblings who participated in her study. "Sharp pangs of jealousy were reported by siblings who perceived that the ill child was being favored with attention and gifts" (p. 269). Rodilsky (2005) documented parental report of jealousy in siblings visiting their ill brothers or sisters in a Pediatric ICU. Montgomery (2000) documented the

jealous feeling of a 12 year old sibling for all the attention and gifts the brother received in the Pediatric ICU. Lehna (2010) studied dyads of children who sustained serious burns and their siblings. Findings showed that 15 out of 21 siblings who had mothers reported receiving equal parental treatment from the mother; 8 out of 15 siblings who had fathers reported receiving equal parental treatment from the father, and 7 out of 15 reported that the father treated one or the other differently.

Need for validation and recognition.

Bank and Kahn (1982) stated, "Through the sibling relationship, one gets the sense of . . . being a distinct individual" (p. 15). Furthermore, a person's "core self begins to develop early in life, [and] is based on meaningful experiences with siblings and parents" (Bank & Kahn, 1982, p. 59). This need of siblings to develop their own identity is analogous to the subtheme which was identified in the current study regarding the siblings' need for *validation and recognition.* In Gelmann's (2000) study, a sibling asked "Does anyone care about me? . . . I'm a person too" (p. 80), which is very similar to a statement made by a sibling in the current study, i.e., "I feel like I should be important, too . . . ."

Information needs and communication.

The siblings' *need for information* was confirmed in studies of children with inflammatory bowel disease (Akoberg, Miller, Firth, Suresh-Babu, & Thomas, 1999), siblings of critically ill children (Kleiber, Montgomery, & Craft-Rosenberg, 1995), siblings of acutely hospitalized children (Montgomery, 2000), and siblings of traumatically injured children (O'Hara et al., 1991; Johnson, 1995).

Sleep.

Changes in *sleeping arrangements* and *sleeping patterns* regarding siblings of ill or hospitalized children were not found in the literature, with one exception. Morrison (1997) reported that some of the stress experienced by siblings of hospitalized children manifested itself as "sleeping problems" (p. 27); however, no description of the sleeping problems was provided. Findings found that "siblings who visited the child more frequently (> 2) experienced more difficulty sleeping ($p = 0.05$)" (p. 27).

Changes and life being different.

O'Hara et al. (1991) documented siblings' experiences related to living with a survivor of a Traumatic Brain Injury. One sibling explained that after his brother became head injured, his own life changed. He said, "It has changed my life in several different ways. When you live with a head injured person it really changes your life" (p. 9). He talked about new responsibilities and his personal time becoming restricted. Changes related to *increased responsibilities* for siblings regarding general tasks and chores around the home and changes related to helping out with the injured brother or sister were also documented in the literature (Fleitas, 2000; O'Hara et al., 1991; Gill & Wells, 2000).

Gill and Wells (2000) examined the experiences of 8 siblings who lived with a head injured brother or sister. The siblings ranged in age from 14 to 30 years; 4 were school-age at the time of injury and 2 were adolescents at the time of injury. Findings included a "change in the sibling" (p. 48) and "changes in the way the well sibling

went about day-to-day life" (p. 48). The authors identified one overarching theme of life being "forever different" (p. 49). Gill and Wells' themes and metathemes were similar to this study's subtheme of *changes in daily routines* and metatheme of *a different world.*

Growth and maturity.

One of the metathemes found in this study, *a growth experience* for siblings, is related to "changes in self" (Gill & Wells, 2000, p. 48) reported in the literature. Siblings talked about an increase in self-awareness and a change in priorities which "prompted them to rethink who they were, what they wanted to do, and why they were doing it" (p. 51). Similarly, a sibling participating in the O'Hara et al. study (1991) spoke about his brother's head trauma and said, "It forces you to change yourself and constantly rethink what you're doing at certain times because you can't always live a carefree life like you want to. . . . That's basically how it forced me to grow and it has helped out a lot" (p. 9). Fleitas (2000) found themes of independence and maturity displayed by siblings of ill children and documents the expanding responsibilities taken on by the siblings. These findings relate to the metatheme of *an opportunity for growth* for the well-school age sibling.

Other themes & subthemes supported by the literature.

"Emotional turmoil" (Gelmann, 2000, p. 78) was one of the themes uncovered by Gelmann in her study of disabled and hospitalized children. As part of emotional turmoil, siblings in her study spoke about being alone while parents were at

the hospital, which compares to the subtheme of *loss* of parental contact in the current study.

A sibling in Montgomery's (2000) study reported needing more unit activities for siblings. This was similar to the idea suggested by a sibling in the current study about the establishment of a Sibling Lounge with activities for the sibling and child to do together.

The study subtheme of the sibling *having fun* and playing with the injured child while at the hospital was found in one study. In her study of siblings of children with burns, Lehna (2010) found that "play and activities between the siblings after the burn injury were often the same or similar as those prior" (p. 248). Play provided a sense of normalization to the patterns of daily living.

Chapter VI

DISCUSSION

In this study, themes were identified by analyzing the spoken words of the well school-age siblings of a traumatically injured, previously healthy child. So that this experience might be better understood from a developmental perspective, findings were interpreted within the frameworks of widely accepted and preeminent developmental theories.

Family Systems Theory

According to widely accepted family systems theory, family members and their relationships are interrelated, complex and interconnected. Bowen (1978) stated that "all important people in the family unit play a part in the way family members function in relation to one another" (p. 259). "The family *is* a system in that a change in the functioning of one family member is automatically followed by a compensatory change in another family member" (p. 260). Applying this theory to the current study, the *one family member* can be considered to be the *traumatically injured child,* and the *other family member* can be thought of as *the well school-age sibling.* It can be determined by an examination of the themes derived from the spoken words of the siblings, that sibling participants experienced a number of the compensatory changes to which Bowen referred. These changes were documented, and included practical changes in sleeping arrangements, engagement in additional household chores and

responsibilities, altered morning routines, and changes in the transportation patterns to and from school. More internalized changes experienced by the siblings were: feelings of sadness and empathy, the development of a closer sibling relationship with the affected child, and feeling good about self for contributing to the family activities.

Developmental Theories

Knowledge of child development and theoretical frameworks that seeks to explain the cognitive and social development of children is essential to the analysis and understanding of the school-age siblings' experiences.

Cognitive theory: Piaget.

Piaget's (1951/1974; Piaget & Inhelder, 1966/1969) theory regarding the intellectual development of children can be used as a framework to help interpret subtle differences found between the findings in this study regarding school-age siblings versus the findings of other studies done with adolescents. Piaget theorized that school-age children perceive and process the world around them in a more concrete way than older adolescents. Adolescents, on the other hand, have more capacity for abstract thinking and are able to think and reflect upon the world around them in a more conceptual way. As Piaget (1951) stated in his discussion on the developmental nature of perception, "comparisons, analyses, anticipations, etc., . . . grow regularly with age" (p. 76). A comparison between the findings documented in the literature for these distinct age groups showed that Piaget's concepts were upheld. Although there were some exceptions, generally findings from this study were

reflective of concrete operations of thought and interpersonal relations Piaget reported in school-age children, i.e., the concrete operational stage of cognitive development. "The operations involved . . . are called "concrete' because they relate directly to objects and not yet to verbally stated hypotheses . . ." (Piaget & Inhelder, 1966/1969, p. 100). The experiences shared by the school-age siblings were related to how everyday life changed for them and what they felt and experienced in the moment. They discussed realistic and practical ways that their lives were affected by the traumatic injury of their brothers or sisters. For example, siblings talked about how *they felt* at the moment when seeing their brother or sister in pain. They talked about how *their routines* changed, and how *they traveled* to school by themselves after the injury. They spoke about a new bedroom, or a new chore around the house. Most of these topics were very tangible and immediate in nature. None of these siblings spoke about how life had changed in a more permanent way or the meaning of this change for the future of themselves or their family. They did not conceptualize on a deeper level or integrate these immediate changes into a more broadly held view of their life's trajectory vision. Furthermore, they did not postulate about the meaning of this experience in their lives. The experience for school-age siblings was from the perspective of *the here-and-now* and how it affected their present everyday lives. Conversely, findings from studies which focused on adolescents revealed more of the meaning of this experience in their lives, and hence, were more reflective of the Piaget's formal operational stage of cognitive development. In Gill and Well's (2000) study, adolescents discussed *changes in self* and *increased self-awareness*,

influencing them to "rethink who they are, what they wanted to do, and why they were doing it" (p. 51). Similarly, in Johnson's (1995) study, an adolescent brother talked about becoming more aware of his own mortality. These findings demonstrate the higher level of abstract thinking reported by Piaget, and illustrate the adolescents' capacity to integrate their experiences into a broader life-view and find meaning in the experience. In general, the capacity of adolescents to think, reflect, and ponder the experience on a deeper level than school-age siblings was evident.

Psycho-social theory: Erikson

Erikson (1963) argued in his developmental theory, The Eight Ages of Man, that the major developmental task for school age children is the development of a sense of industry versus a sense of inferiority. Threads of Erikson's theory ran throughout the findings of this study. A sense of industry was fostered in the participants by the changes in normal routines which were connected to the siblings' assumed additional household chores or tasks. These additional responsibilities, when successfully carried out, provided the means for the school-age siblings to feel confident about themselves and become competent, contributing members of the family unit. For example, one sibling commented on his new duties within the family routine: "But now, I kind of like helping out more." This comment suggested an increased sense of pride and accomplishment felt by the sibling related to his overall contribution to the family system regarding household tasks. Generally, the themes discovered in the data were connected to Erikson's developmental stage of school-age children. Studies with adolescents conducted by other researchers (O'Hara et al.,

1991; Johnson, 1995; Gelmann, 2000; Abrams, 2009) reported themes which were more introspective and reflective of self-discovery, more closely aligned with Erikson's task of adolescents regarding the development of a sense of identity.

Development of identity.

Siblings in this study asserted their need and desire to be acknowledged as their own person, separate and distinct from their brother or sister, and to have their importance recognized. In their classic work *The Sibling Bond*, Bank and Kahn (1982/1997), confirmed the manifestation and importance of this need and stressed each sibling's need for a "core identity" (p. 59).

The sibling bond.

Bank and Kahn described middle childhood as:

> the most uneventful period in the sibling connection of any child. Short of any catastrophic change in a brother or a sister due to a physical illness or emotional upheaval, siblings in middle childhood and pre-adolescence seem to live with the illusion that their relationship will never change. (pp. 63-64)

Siblings in this study did, however, experience a *catastrophic change in a brother or a sister due to a traumatic physical illness*, so it is not surprising that changes in the sibling relationship were noticed by the siblings. Siblings remarked on these changes and described them as *becoming closer* and the *desire to spend more time with the injured brother or sister*.

In Bowlby's (1979/2005) classic book, *The Making and Breaking of Affectional Bonds*, the author traced the history of the emotional life of children as

interpreted by Freud, who he explained first introduced the world to *Sibling Rivalry* as a concept, and discussed the sibling bond. Bowlby stated, ". . . in our early years it is the rule and not the exception that towards both our siblings and our parents we are impelled by feelings of anger and hatred as well as those of concern and love" (pp. 10-11). This insight into the essence of the sibling bond was upheld in the findings of this study. Comments made by the siblings reflected the polarization of their feelings toward their injured brother or sister and the evolving sibling bond. One sibling said, "My sister would get mad at me and she will just hit me and then I get mad. Usually, I don't really like her." Later, this same sibling made what appeared to be a contradictory statement: "When I saw her, I was like, this isn't the girl I kept fighting with. It kind of drew me close to love her." However, considering the conflicting nature of the sibling bond as put forth by Bowlby, these contrary statements were interpreted as normal and common to many sibling bonds.

Discussion of the Literature

The responses of siblings in this study were, in part, similar to those reported by other siblings of patients with serious illnesses, both acute and chronic, and siblings of children with cancer. This study confirms some of the similarities and differences.

The theme of *compassion*, and the child's capacity to embrace the wide range of feelings that encompass compassion such as *sadness* and *empathy*, has been documented in other studies (Murray, 1998; Fleitas, 2000; Montgomery, 2000;

Morrison, 1997) of siblings of hospitalized children. An increase in compassion was reported by Sargent et al. (1995) with siblings of children with cancer. On the contrary, adult siblings living with a brother or sister who had a Traumatic Brain Injury did not report *sadness* as a response to their sibling's traumatic injury, but rather reported "having hope" (Jumisko, 2007, p. 364) that their brother or sister would improve and/or have a good life. Since hope is a future-oriented response, it is not surprising that school-age siblings, who are in the concrete operational stage of cognitive development, reported responses such as sadness which are more present-oriented and self-oriented. Szagun (1992) studied how sadness is conceptualized by children and found that young children expressed sadness in response to "long-lasting and life threatening distress situations" (p. 1190). This is in accord with the subtheme of sadness identified in this study.

Although the siblings in this study did not use the terms *stress* or *stressful* to describe their experience, they definitely revealed how *hard* or *difficult* the experience was for them. Other studies (Sargent, 1995; Fleitas, 2000; Morrison, 1997) done with siblings of acutely ill or hospitalized children reported an increase in the stress levels of the siblings. Essentially, the findings regarding *stress* were synonymous. Furthermore, Sargent (1995) reported that siblings of children with cancer described the worst thing they experienced was seeing their brother or sister receive cancer treatments and watching the effects of treatment. The average age of Sargent's sibling informants was 10.7 years. Similarly, the school age siblings in the

current study said that seeing their brother or sister receive treatments was difficult for them.

Gelmann (2000) identified the theme of "emotional turmoil" (p. 71) in siblings of hospitalized children. Those siblings, who were mostly adolescents, spoke of the difficult loss of their brother or sister as they previously were, and that the experience caused them to frequently cry. However, the school-age siblings in this study connected the difficulty of the experience with seeing their brother or sister in pain from their injuries and medical treatments. Using Piaget's (Piaget & Inhelder, 1966/1969) theory of intellectual development as a framework, these two studies can be interpreted and compared. The adolescents in Gelmann's study were cognitively able to use abstract thinking and make sense of the meaning of what they experienced on a deeper, existential level; whereas, the school-age siblings participating in this study used concrete operational thinking and exhibited less ability to integrate the meaning of the experience in a profound way. Rather, they responded to the more visual and empirical images before them in a concrete, age-appropriate way.

Sibling rivalry and jealousy were reported as strong themes in this and other studies (Murray, 1998; Akobeng, 1999; Fleitas, 2000; Rodilsky, 2005). Since sibling rivalry is considered a normal and common occurrence in sibling relationships (Bank & Kahn, 1982/1997; Bowlby, 1979/2005) it seems legitimate that findings in this and other studies documented the conflicting responses of siblings including jealousy and love, rivalry and caring. Sibling rivalry is one of the constituents that form the sibling

bond, and even in the presence of the current family medical crisis, sibling rivalry remained a part of the normalization process.

A heightened *sense of responsibility*, which was displayed behaviorally as the assumption of additional tasks within the family household routines, was confirmed in this and other studies (Sargent et al., 1995; Murray, 1998; Fleitas, 2000; Gill & Wells, 2000;). A chance to establish early independence, as part of the developing sense of responsibility, was explained by one sibling in the study, who said, "So I get myself up, get myself some breakfast, wake up my brothers, and tell them I have to be ready for the bus soon. And, I need someone to walk me down to my bus stop." This change in morning routines provided an opportunity for the sibling to become more self-reliant and responsible.

The study finding regarding the siblings' *need for information* concerning what was happening with their brother or sister was well documented in related sibling studies (O'Hara et al., 1991; Johnson, 1995; Kleiber, Montgomery, & Craft-Rosenberg, 1995; Akobeng et al., 1999; Fleitas, 2000; Montgomery, 2000; Abrams, 2009). In the study by Akoberg et al., most siblings suspected that their parents purposely kept information about their brother or sister's chronic illness from them and this was a real concern to the siblings. The siblings in this study never spoke about such suspicions. Montgomery reported that siblings felt they received incomplete information about what was happening. Johnson reported the siblings' need to be informed and involved.

The *need for recognition and validation* of the siblings' own identities, which was partially connected to the pattern of communication siblings in the study experienced with healthcare personnel, was marginally confirmed in two other studies (Fleitas, 2000; Abrams, 2009;). Fleitas reported that siblings became resentful and lonely because they were ignored by physicians and nurses. Abrams presented case studies of families with children who had serious mental illness, and discussed the difficulty that some siblings had establishing a separate and personal identity. The siblings in this study spoke about being ignored at times by nurses. Their concern for this was understandable since school-age siblings still look to adults for validation of self and confirmation of their importance.

The sibling relationship was never weakened; in fact, siblings reported that the experience fostered their relationship with their brother or sister and that they became closer through the experience. Although siblings in the study were very clear about feeling closer to their injured sibling through the experience, only one other study (Gill & Wells, 200) reported a similar finding. In that study, some of the siblings of children with a Traumatic Brain Injury reported feeling a "new closeness" (p. 51) toward their injured sibling; however, some siblings in the same study reported feeling "less close" (p. 51).

The subtheme of *loss* specifically regarding parental contact and missing their parents was strong for the siblings in this study. This finding was not confirmed in other studies; however, since many sibling studies were done with adolescents, this is not surprising. Adolescents are developmentally more independent than school-age

siblings, especially regarding their parental relationships and typical daily contact. Gelmann (2000) reported a theme of loss in her sibling study; however, those siblings explained that their sense of loss was felt toward the pre-hospitalized state of the brother or sister and the pre-illness family system.

The study's metatheme regarding *a growth experience* was well confirmed in the literature. Murray (1998) described the *personal growth* of siblings of children with cancer, whereby one adolescent sibling felt that "the childhood cancer experience made her grow up quicker and gave her responsibilities within the family" (p. 222). Siblings in Gill and Wells' (2000) study described changes in self related to added responsibilities and self-awareness. O'Hara et al. (1991) reported siblings' increased self-awareness and growth related to the Traumatic Brain Injury of their brothers or sisters. Similarly, Fleitas (2000) reported a growth experience for siblings related to increased independence and autonomy throughout the hospitalization of their brothers or sisters.

There was only 1 other study (Morrison, 1997) which reported any change in sleep patterns for siblings. Morrison reported "sleeping problems" (p. 27) as an outcome of the stress experienced by siblings of hospitalized children without further description or discussion. The change in sleeping arrangements experienced by the siblings in this study was not confirmed by other studies.

The *constants* documented in this study included the siblings' *school life*, *fun* and *play*, and continued socialization with new and old *friends*. These areas of constancy in the siblings' lives enhanced a sense of stability and normalcy for the

siblings and appeared to serve as mediators of stress. In her study of sibling experiences after childhood burn injuries, Lehna (2010) categorized these very activities as "areas of normalization" (p. 248) for siblings, and discussed the resumption of these age-appropriate activities as part of the normalization process siblings underwent after the burn injuries of their brothers or sisters. Lehna stated: "Normalization refers to the process of establishing a pattern of daily living that minimizes the consequences of the chronic illness (such as a burn injury)" (p. 248).

School-age children generally like to play and have fun, and often, making and finding fun is how children experience the everyday activities that fill their world. This natural activity of *having fun* remained a part of the siblings' lifeworld throughout the experience, and became a mediator of stress for the siblings as exemplified in the advice one sibling offered to other children whose siblings experienced a traumatic injury. She said, "They should have more fun, instead of, like, remembering their injuries. Having fun is more important. It is a good thing." This sibling recognized the therapeutic element of fun and expressed her wish for other siblings and affected children at the hospital to have "more fun." Another sibling played ping-pong frequently at the hospital with her father, greatly enjoying it. Since her affected sister was functioning physically and cognitively at a low level, playing ping-pong with her dad provided fun for the sibling and an escape from the intense tone which pervaded her sister's hospital room. When asked about the play time spent with her sister, one sibling claimed that playing with her sister, "Makes me feel like this never happened. That's how it feels to me." Again, this statement

seemed to validate the therapeutic nature of play and how it can be meaningful for siblings experiencing this phenomenon. For this particularly introspective sibling, the fun aspect of playing with her affected sister provided a brief, albeit fleeting, respite for her from an otherwise difficult experience.

The subthemes of having *other caring adults* in contact with the siblings during this experience and the *constancy of the siblings' school lives* can be understood as something referred to in the literature as *protective factors*. The literature was rich with descriptions of protective factors which mediate between stress and competence, and between risk and resilience. Luthar, Cicchetti, and Becker (2000) emphasized the "importance of close relationships with supportive adults, effective schools, and connections with competent, prosocial adults in the wider community" (p. 545) as mediating factors of stress which help develop resilience in children. Similarly, Masten and Coatsworth (1998) identified several protective factors including attachment with caring adults and social competence with peers. Howard, Dryden, and Johnson (1999) stated that "the more protective factors that are present in a child's life, the more likely they are to display resilience" (p. 310). The 7 siblings in this study had many of the mediating factors present in their lives that were discussed in the literature. The subtheme of *other caring adults* in the life of the siblings was understood in the study as grandparents and extended family and friends rallying to assist the family and siblings. Siblings spoke about continuing to have contact with old friends, especially at school, and establishing new friends at the hospital. Siblings related that *school life* was an unchanged, stable factor in their

lives. These factors can be understood as what the literature labels as *protective*.

Fear, guilt, and embarrassment were reported in other sibling studies (Johnson, 1995; Sargent et al., 1995; Fleitas, 2000; Abrams, 2009), but were not reported by the siblings in this study. It is somewhat surprising that *feeling guilty* never emerged as an issue for any sibling in the study since 4 out of the 7 siblings were either nearby, or witnessed the traumatic incident which caused the injury to the affected child.

There appeared to be no gender related qualitative differences or conflicting findings in the data collected from the 2 boys participating in the study as compared to the data collected from the 5 girls. A comment entered into the researcher notes regarding the transcription of the interview completed with one of the boys in the study, reads: "This boy had many of the same feelings as the girls I interviewed. He was sad to see his brother hurt. He was happy to see his brother doing well. He feels closer to his brother now."

The findings in this study were concrete in nature and sibling-focused. Overall, the siblings appeared to be coping competently with the experience of being the well school-age siblings of children with traumatic injuries during the early rehabilitation phase. Although described as *a difficult experience*, they revealed no serious behavioral, social, or emotional problems during their interviews. Although this was *an emotional experience* for the siblings, they were not in the depth of *emotional turmoil* as described in other studies (Gelmann, 2000; Gill & Wells, 2000). Siblings focused on how the experience affected them directly, speaking about their

sadness and *compassion* for others. They did not look forward and anticipate how life may change more permanently for their families or for themselves. They spoke about new and increased chores which they assumed, which highlighted their *sense of responsibility*. The increased responsibilities, along with their desire to help, and with the *empathy* felt by the siblings, were a foundation for *the growth experience* for the siblings. The constancy of the routines which remained unchanged, such as *school life for the sibling*, and *having fun*, along with the *contact with other caring adults*, appeared to be part of the "tool kit" that supported siblings through this experience and fostered their coping skills. The sibling relationship with the affected brothers or sisters was perceived by the well siblings as becoming closer as a result of this experience. The needs expressed by the siblings centered on *more involvement and better information* regarding the affected children's traumatic injury and care.

In a panel discussion (O'Hara et al., 1991) held with siblings of children with Traumatic Brain Injuries years after the injuries occurred, one brother shared this comment: "I wish I had the opportunity back then to express myself like I am today" (p. 11). A sibling in this study expressed a similar view when she said to the researcher, "I hope we get together again. This was so much fun." Sharing her thoughts and feelings regarding her experience was a positive activity for this sibling, and one she wanted to engage in again.

Chapter VII

THEMATIC REPRESENTATIONS IN THE CULTURE

Triangulation of Data with Artistic Sources

According to Van Manen's (1984; 1990) approach to phenomenology, the researcher can add meaning and understanding to the thematic analysis by seeking out descriptions of the uncovered themes in artistic sources. With this intent, I went to sources found in the lifeworld of children, such as children's literature, art work, songs, children's television programming, and children's websites, in search of the themes. Many of these sources contained stories and narratives related to the phenomenon under study, some of which are the spoken words of other siblings. Literature, self help books for children, art, television, and internet resources support the metathemes that emerged from this research.

Children's literature.

Kira-kira.

A search of popular children's literature revealed a gap in literature written specifically about siblings and sibling relationships in the context of traumatic injuries. However, a very close theme was uncovered in the fictional novel, *Kira-Kira* (Kadohata, 2004), whose author was awarded the John Newberry Medal in 2005 for the most distinguished contribution to American literature for children. This book was written in first-person narrative style from the point-of view of Katie, an eleven year old girl growing up in the 1960s in Georgia. Katie tells the story of her relationship with an older sister throughout family tragedy, including her sister's illness, and

personal challenges. "Graceful prose illuminates complex relationships, most notably between the two sisters. Katie's remarkably authentic voice changes to reflect both her deeper understandings and her growing sense of self over a span of almost 10 years" (American Library Association, 2011).

Kira-Kira (Kadohata, 2004) incorporated some of the same themes and subthemes that were revealed in the data of this study. One of these themes is *compassion*, shown by Katie though the attentive care she rendered to her sister during her illness. Katie explained that when her sister felt tired from being anemic, "Every day I sat by her bed and fed her rice and liver" (p. 129). She further recounted:

> Lynn felt so tired, she didn't want to get out of bed. I cooked her an extra helping of liver and told her to chew well. . . . She didn't even have the energy to chew. I even offered to chew it for her. (pp. 120-121)

As was done by one of the sibling participants in the study, Katie helped her mother care for her ill sister. She explained that when her sister "wasn't so well, my mother and I put her on a sheet. We would each take an end of the sheet and carry her outside." (Kadohata, 2004, p. 179). Katie's compassion was revealed when she worried about her sister: "I worried that Lynn was lonely by herself in the bedroom" (p. 130).

One of the strongest subthemes identified in the study was *sadness,* which was experienced by Katie while going through the family crisis regarding her sister's

illness and hospitalization. She said, "I wondered if anyone else in history had ever been as sad as I was at that moment" (Kadohata, 2004, p. 199).

Similar to the siblings in the study, Katie acknowledged, "I hated being alone. I loved having a brother and a sister" (Kadohata, 2004, p. 144). Katie also welcomed *fun*, another theme identified in the study, saying, "School was boring and homework was boring. Playing with my brother and sister was fun" (p. 61). She experienced a s*ense of loss* regarding her parents when they would spend much time away from the family working at their jobs, as she explained they "leave for work every day very early in the morning. Our father would work two jobs, and our mother would work overtime if it was available. I already missed them" (p. 41).

Like many of the families in the study, Katie's family changed the *sleeping arrangements* for the family to accommodate the ill child. Katie and her brother slept in the living room so that their ill sister could have her own room (Kadohata, 2004, p. 130). Like the siblings in the study, Katie had *trouble sleeping* at times, "When I worried, I couldn't sleep" (p. 93).

The family in *Kira-Kira* (Kadohata, 2004) faced difficult circumstances related to jobs, finances, housing, and serious illness of a child. Like many of the families in the study who experienced a complicated family crisis, they relied upon extended family and other *caring adults* for help and assistance. Katie and her brother stayed with their aunt and uncle when their sister was hospitalized (p. 127), and neighbors helped out with babysitting.

Katie looked up to her older sister and went to her for information and

answers, just as some of the siblings in the study did. She said, "I liked to ask Lynn questions, because she knew so many answers" (Kadohata, 2004, p. 57). But when it came time to *getting information* about her sister's illness, just as the siblings in the study used their parents as a source of information, Katie learned about her sister's illness from her father (p. 176). As a response to the family crisis, Katie assumed *new tasks and responsibilities* and helped out around the house in new ways, which is consistent with the findings of the study. Katie started cleaning the kitchen, doing the dishes (p. 214), and cooking dinner every night (p. 227).

What about me? When brothers and sisters get sick.

What about me? When brothers and sisters get sick (Peterkin, 1992) is a book written by a Child Psychiatrist in Montreal, Canada. It was published by Magination Press, an imprint of the Educational Publishing Foundation of the American Psychological Association. Written is storybook style, and aimed at young children, this book is appropriate for younger school-age siblings. It is the story of a young child whose brother became acutely ill and hospitalized. It supported the study theme of *loss*, as the sibling in the story missed her parents when they were away from her at the hospital with her brother. It supported the theme of *having fun*, as the sibling asked if she will be able to play with her brother when he comes home.

When Molly was in the hospital: A book for brothers and sisters of hospitalized children.

When Molly was in the hospital (Duncan, 1994) is another storybook for younger children, based on the real life experiences of the author's family and their

experience when one daughter became ill. The sibling in the story spent time after school with *grandparents and friends' parents*, an activity which she initially enjoyed, as the siblings in this study did. The book supported the study theme of siblings playing and *having fun* in the hospital physical therapy room when visiting a brother or sister.

Views from our shoes.

Views from our shoes (Meyer, 1997) is not a novel or storybook; rather, it is an advice book written both for and by siblings of children with disabilities. The editor, a Special Education expert and the Director of the national Sibling Support Project, collected stories from 27 well, school-age siblings. In the book the siblings share their stories, opinions, and advice for other siblings who have "special needs" brothers or sisters. Some of the study themes were found in their stories.

The *helping* nature of a sibling relationship was commented upon by one 9 year old sibling in a positive way. She said, "What I like about having a sister with special needs is that I can help her" (Meyer, 1997, p. 29). However, siblings also spoke about the *jealously* and *rivalry* which are ever-present in these relationships. A 10 year old sibling wrote about her sister: "My parents give Martha all the attention and give her all the toys she wants when I barely get anything" (p. 41). Similarly, a 10 year old sibling wrote about his sister: "Sometimes I'm jealous of Lindsey" (p. 36).

The siblings who wrote their stories in this book sought *individual validation* and *attention from their parents* just as the siblings in the study did. Addressing this

theme, a 12 year old female sibling stated: "The bad thing is all the attention he [disabled brother] gets. Sometimes I feel left out. People think of me as 'Jacob's Sister,' and sometimes I don't feel like I get enough attention from my family" (Meyer, 1997, p. 64). The *difficult nature* of the experience of having a sister with special needs was emphasized by another sibling when she said, ". . . it adds to what would otherwise be a normal sibling relationship—which is rough just by itself" (p. 41). The *different nature* of the experience was mentioned by a 12 year old sibling, when she said, "Since I have Brian as a brother, my life is a little different" (p. 57). However, the *love for their brothers or sisters* was still part of the experiences the siblings shared. One sibling wrote: "I would just like to say that my Mom and little sister are both disabled and, yes, it is hard but I love them both" (p. 51).

The sibling slam book.

The Sibling Slam Book (Meyer, 2005) is a similar book written by siblings of children with disabilities. Eighty adolescents, primarily from the United States and a few from Australia, New Zealand, Canada, and England, answer poignant questions about their experiences being the sibling of a brother or sister with a disability. The range of disabilities included: Autism, Cerebral Palsy, Chromosomal Disorders, Down Syndrome, Attention Deficit Disorder, and other chronic disabilities; no siblings of children with traumatic injuries were included in the group. Some of the experiences and themes gleaned from this book were similar to those in the study.

The study's finding regarding the sibling love and care for the affected child was found in the words of one sibling, who has both a brother and a sister with autism

(Meyer, 2005, p. 24). When asked, "If you had just one day when your sibling didn't have a disability, what would you chose to do on that day?" (p. 138), she answered:

> I'd tell them how much I love them so I could look back on that day and remember that for one day, they knew they were loved, and that for one day, I could hug them, and have them fully understand what that hug really meant. (p. 139)

Answering the same question, the theme of caring was evident in the words of another sibling:

> I would just want to hang out with him and get to know him better. You know, just talk as two regular people do. So he could understand a bit more about me and I could understand more on him. (p. 140)

Another sibling answered the same question by stating that she "would really like to have a long conversation with him [brother]. I would probably spend time together in a restaurant (so we can talk)" (p. 138), mirroring the study's finding about siblings wanting to spend time with the injured brother or sister. The *love* of the sibling for the affected child was found in the words of a sibling who had an adopted sister with many functional disabilities (p. 21). When describing her sister, she said, "I would NEVER trade her for anyone else. I LOVE HER SO MUCH" (p. 21)!!!

The study finding regarding *taking on additional responsibilities* was found in the words of the siblings of *The Sibling Slam Book*. One sibling said, "The responsibility definitely stinks" (Meyer, 2005, p. 141), while another said, "After a while, I became the second mom—always helping my dad and mom" (p. 141).

The subtheme regarding the *difficult nature of seeing a brother or sister in pain* or discomfort was mentioned by one sibling who has a younger sister with multiple disabilities (Meyer, 2005, p. 19). When asked, "What is the toughest thing about being a sib?" (p. 141) she replied, "Seeing her suffer when there's nothing I can do except comfort her" (p. 141). Another siblings answered, "Watching my sib go through treatments and not be able to do anything" (p. 141), which is similar to remarks made by siblings in the study.

Siblings: You're stuck with each other, so stick together.

Siblings: You're stuck with each other, so stick together (Crist & Verdick, 2010) is an advice book for siblings targeting children from 8 to 13 years of age. It is co-authored by a Child & Family Psychologist and a veteran Children's Writer. The authors presented universal problems and situations that many young siblings, of all types, experience in their relationships with their brothers and sisters, and offered sage advice to cope with these common situations in a playful and fun way. Attractively illustrated in cartoon-like style, written at the reading level of grades 3 to 4, it is appealing and fun to read. Some of the study themes and/or subthemes are similar to the problems discussed in this book.

The subtheme of playing and *having fun,* especially with a brother or sister, was one of the study themes. Similar to the siblings in the study, some of the advice given to readers of this book—the general sibling population—presented the idea that "sibs are there for you" (Crist & Verdick, 2010, p. 9). They are available to play with and "share fun times" (p.9). Selected excerpts from school-age children are included

in the book. One 9 year old commented: "The best things about having an older brother are that he keeps me company, he plays with me" (p. 78). Another 11 year old said, "One nice thing about having a sister is that I always have someone to play with" (p. 78). The similar theme of *caring* and watching out for one another was discussed by the authors when they said, "Sibs look out for each other—and up to each other" (p. 13).

Closely related to the findings regarding helping, and being involved with a brother or sister, Crist and Verdick (2010) talked about the helping nature of siblings. They stated, "sibs can help you" (p. 10) with chores, homework, problems, and advice. Moreover, the authors spoke about how all siblings take on "age-appropriate" (p. 56) responsibilities as they advance in age (p. 57) regarding household chores. This theme correlates with the study finding concerning the school-age sibling taking on additional responsibilities during the early weeks of the traumatic injury crisis with a brother or sister.

In a special section of the book dedicated to bonding with brothers or sisters who have a disability, Crist and Verdick (2010) addressed *the difficult nature* of the experience, which was closely related to the study theme of *a difficult experience*:

> Some brothers or sisters have special problems (sometimes called "disorders") that can make life more difficult for them—and for you. Maybe your sib has a physical disability . . . This isn't easy for anyone in your family. Your sib struggles, your mom or dad has more challenges than most parents, and you—

> as the brother or sister of someone with special needs—get caught up in it all. (p. 106)

Another difficult topic regarding siblings was discussed by Crist and Verdick (2010) in terms of normal *sibling rivalry,* a subtheme of the study. They stated:

> Admit it: You get jealous of your brother or sister, don't you? That's totally normal. All siblings feel jealous at some point, even when they're grown up and supposed to be acting like adults. The truth is some sibs feel jealous every day. (p. 49)

In addition to sibling rivalry, other study findings such as *love of the affected brother or sister, taking on more responsibilities*, and *support from caring adults*, underpin the following statement which was directed toward siblings with brothers or sister with special needs:

> No matter how much you love your sib, there will be times when you feel jealous, frustrated, embarrassed, or ignored. . . . At times, you might have to act as your sib's caretaker—and that's a lot of extra responsibility. You have more to handle than many kids your age. But with help from your family, teachers, or a counselor who can talk to you about your feeling, you'll have the support you need to stay strong. (p. 107)

The metatheme of *a growth experience* was clearly present in this book. Crist and Verdick (2010) referred to growth when they said, "There's room to grow. The

relationships you have with your siblings help teach you about yourself and the world. You learn about handling strong emotions . . . ." (p. 13).

Finally, Crist and Verdick (2010) emphasized that through all of the difficult and challenging situations and experiences school-age children commonly have with siblings, the *love for the brother or sister* prevails. They said: "The important thing to know is that you and your siblings are linked by more than just your parent(s). . . . You're connected by . . . love" (p. 6). A 10 year old sibling said of her brother: "I love my brother. Life wouldn't be the same without him around" (p. 79).

Other popular literature.

Day by day: Children tell their journeys of faith and determination living with a sick sister or brother.

Day by day: Children tell their journeys of faith and determination living with a sick sister or brother (Frisbee, 2008) was written by a social worker who had a personal interest in this experience based on her own childhood experience. Frisbee interviewed several children living with a brother or sister who was chronically ill and wrote about their experiences, quoting many passages directly from their words. The study theme of *sadness* was supported, as expressed by the siblings interviewed.

Art.

Several art works were found that support the themes and subthemes that emerged from this study.

An artistic representation of siblings is depicted in the artwork titled *Siblings* by Klee (1930). This expressionistic painting shows 2 siblings intertwined while

walking along with 4 legs, 4 eyes, a connected head and body, and one heart, suggesting the intimate and close nature of the sibling relationship. Another close, affectionate sibling relationship is portrayed in the impressionistic painting, *The Sisters* (Cassatt, circa 1885). This American painter's work shows 2 young sisters in close body contact with one sister's arm upon her sister's shoulder, suggesting an intimate bond. The expression on the face of the child on the left may be interpreted as deep concern for her sister. A pastel drawing done by French artist Serret (19th century), *Three Children in a Landscape*, illustrates a pastoral scene of 3 young children sitting on a hillside. The older girl is holding a younger child on her lap while looking toward another younger child nearby. The art work suggests a loving gentle affection of one child to the two others. Another French artist in the 19th century, Bouguereau, sketched *Two Sleeping Children* in black and white chalk, representing two of the subthemes discovered from the research study: a *close sibling relationship* and altered sleeping patterns, that is, siblings *sleeping* together.

The enjoyment of siblings being together is represented by the oil painting *Two Sisters on a Terrace* (Renoir, 1881), which shows an older and younger sister sitting in a garden together enjoying each other's company. This artwork relates to the study finding whereby siblings like to be with their brother or sister and want to spend time with them. Siblings playing together and *having fun* can be seen in many artworks from Spain (Sorolla, 1903; Sorolla, 1909), Denmark (Frolich, 19th century), France (Morisot, 1886), and the United States (Potthast, n.d.; Tucker, c. 1840-1844).

Discovering the subtheme of children *having fun* in several works of art from around the world emphasizes the universality of this common experience.

A reflection of a painful and traumatized childhood is found in an art piece done by a contemporary American artist (Schmidt, 2000), crafted out of recycled ripped rags and hooked onto cloth. The colorful fabric depicts two sisters as children clinging to one another for solace, stability and *comfort*, and symbolically represents their childhood *sibling relationship* (L. Schmidt, personal communication, February 6, 2003). *Childhood sibling relationships* can also be found in artwork done by contemporary children. *The Global Children's Art Gallery* (The Natural Child Project, 2011) contains 1,120 pieces done by children from over 70 countries. Perusing the catalog, many drawings can be seen which focus on the theme of *brothers and sisters*.

Children's television programming.

The popular children's television program, Sesame Street, presented several threads of programming over the years relating to relationships of brothers and sisters and sibling issues. In one story line, *I'm a Big Girl Now* (Sesame Workshop, 2011), two of the main adult characters from Sesame Street, Gordon and Olivia, highlight their relationship growing up together. In the video, Gordon says to Olivia:

> You're my kid sister. You're three years younger than me. . . .
>
> Don't forget, when you were small, I washed your face, I protected you, I took you to school. I helped you with everything. . . . I taught you everything you know! (Sesame Workshop, *I'm a Big Girl Now,* 2011)

In the video clip, the siblings sing a song about growing up and their changing relationship. Content from the song includes: the older brother taught his sister how to tie her shoes and how to climb a tree, he fed her, he helped her to cross the street, and he kissed her when she skinned her knee. The theme of the song highlights a supportive relationship between the siblings which includes helping, caring, loving, and teaching. Olivia, speaking to Gordon, tells him that even though she is "a big girl now" (Sesame Workshop, *I'm a Big Girl Now*, 2011) and all grown-up, she has not changed completely. Gordon asks, "What do you mean?" (Sesame Workshop, *I'm a Big Girl Now*, 2011) and Olivia answers, "Well, I still love 'ya!" (Sesame Workshop, *I'm a Big Girl Now,* 2011).

Brothers and Sisters (Sesame Workshop, 2011), is a 2 minute video accompanied with song, showing several sets of siblings engaged in activities together as children. The over-riding theme of the video-clip illustrates that brothers and sisters have a relationship forever: at times they help each other, at times they fight with each other, but essentially they love each other. The words of the song support the theme:

> Brother loves sister.
>
> Sister loves brother.
>
> They're always helping each other.
>
> When they're hungry, helping them eat.
>
> When they're dirty, making them neat.
>
> When they're crying, helping them cry.

Good dogs can go astray.

Best friends can move away.

But brothers and sisters are here to stay. [refrain]

Brother and sister, friendly and loving,

with now and then a little pushing and shoving.

Sister loves sister, brother loves brother.

See them hanging out with each other,

Spending some time growing up with each other.

Good dogs can go astray.

Best friends can move away.

But brothers and sisters are here to stay. [refrain]

But brothers and sisters are here to stay! (Sesame Workshop, *Brothers and Sister*, 2011)

Kids Take Care (Sesame Workshop, 2011) is another video clip which showcases several pairs of siblings, some of whom are young children, talking about *taking care of one another*, which was a finding uncovered in the study. Excerpts from the video include: a small girl holding her toddler sister, "I like taking care of my sister 'cause it makes me feel good " (Sesame Workshop, *Kids Take Care*, 2011); a brother saying to his sister with Down Syndrome, "I take care of my sister, Mary Kate" (Sesame Workshop, *Kids Take Care*, 2011); an older brother saying to his sister, "I like taking care of my sister, because she's really cute" (Sesame Workshop, *Kids Take Care*, 2011), and the younger sister responds by hugging her brother.

I Like to Sing (Sesame Workshop, 2011) is a video featuring pop singers Aaron and Nick Carter, talking and singing to the Elmo character about brothers and sisters and how they get along with one another. As they encounter the Two-Headed Monster arguing, Aaron and Nick speak to Elmo:

> [Aaron:] That's some argument. Reminds me a little of us.
>
> [Elmo:] Aaron and Nick Carter argue?
>
> [Nick:] Sure, Elmo. We're brothers. We argue sometimes.
>
> [Aaron:] Yeah, brothers argue. Sisters argue. Brothers and sisters argue. It happens sometimes.
>
> [Elmo:] Really? Why?
>
> [Aaron:] Well, for lots of different reasons. (Sesame Workshop, *Kids Take Care*, 2011)

Aaron and Nick sing a song together about sibling relationships, which ends saying, "What a happy day when me agrees with you" (Sesame Workshop, *Kids Take Care*, 2011).

Sibling issues continue to be an important thread to the programming of Sesame Street; a writer from the show is presently working on a new script dealing with sibling issues (E. Kingley, personal communication, November 5, 2010).

Internet resources.

In the present information explosion age, there exists specially designed websites dedicated to a variety of particular interests and concerns of children and siblings. From these websites, I gleaned stories and narratives written by siblings who

have brothers and sisters with special needs, developmental disabilities, and diverse medical problems. These websites are part of the wide-ranging resources available to siblings which are ever-increasingly utilized as a type of adjunct support for them.

Websites.

Bandaids & Blackboards (Fleitas, 2009), a website designed for ill children and their siblings, was encountered when reading a study (Fleitas, 2000) done by a nurse who was the researcher and the creator of the website.

By networking at the first International Sibling Conference (2010), I was able to learn about international sibling websites in Australia. Many of these sites are used as resource centers, chat rooms, and online communities for siblings of children with disabilities.

The Natural Child Project (2011) website was encountered when searching the World Wide Web for databases containing artwork. This website is dedicated to helping parents with young children be better parents, and also contains an art gallery of work done by children, many of whom are school-age siblings. Currently 1,120 pictures are displayed from 70 countries, depicting the works of children who have drawn themselves with their brothers or sisters in various activities.

The Sibling Support Project (2011) maintains a website with which I became familiar through the writings and presentations of Don Meyer, the Director of the project and founder of Sibshops. This website has stories and comments posted from children who have brothers or sisters with special health needs. The website also sponsors a list-serv for young siblings as a communication tool and online support.

Letters & stories from siblings.

The following stories and comments were written by school-age siblings and were accessed online; as such, they are accessible to other school-age siblings.

Note from Jeffrey.

Several subthemes from the study were found in the writings of a 9 year old sibling in a letter to his mother. Themes expressed were: the *continuing sibling relationship, with normal sibling rivalry*; the need for *recognition and validation*; and the *sense of loss* regarding missing his mother:

> Dear Mom,
>
> Tonight Dad was telling me how hard it was when Trudy was in the hospital. He doesn't think it was hard for me at all. I missed you. I saw her get all these presents. I saw everyone visiting her and babying her, and there was nothing I could do about it. Sometimes I feel so alone and left out and even unloved. I know I'm overreacting, and I know that some people have so much less than me, but it's not my fault I don't have any medical problems. I wish I did!
>
> Love, Jeffrey (Fleitas, 2009, Siblings' Stories: "A Note from Jeffrey," para. 1)

Comments from Ben.

Even though this comment was made by a hospitalized child, the theme of close *sibling relationships* and siblings *missing one another* is evident:

> Can you figure out which one of us is the patient? I'm the older one in the bed, Ben, and my little sister Annie has just made my day. When she told me that she really missed me at home, I told her that she couldn't miss me as much as I missed her. And that's the truth. (Fleitas, 2009, Siblings' Stories: "Comments from Ben," para. 1)

Other themes.

The *involvement of siblings* with their affected brothers or sisters and the *love siblings have for their brothers or sisters* were expressed in the words of another young sibling:

> Whenever he has problems he knows I will always be there to help sort them out. I am one of the luckiest people in the world to have a brother like Jacob. I love him so much. He is the kindest person I've ever met and I hope he never changes. (The Sibling Support Project, 2011, Connect with Other Siblings: "National Siblings Day Celebration," para. 3)

From *Views from Our Shoes (*cited in The Sibling Support Project, 2011, In Sibs' Own Words, para. 21), a 9 year old sibling also expresses her fond feelings for her brother: "Jason is a great brother, and life would be hard to imagine without him." A 10 year old sibling from Australia wrote, "I love my sister despite her disabilities" (Siblings Australia, 2011, Young Sibs: "What other kids say about being a sib," para. 3).

The subtheme of *sibling rivalry* remaining a constant was found in the words a 9 year old sibling with a disabled sister: "I don't like having my sister because she

gets more attention than me" (Siblings Australia, 2011, Young Sibs: "What other kids say about being a sib," para. 5).

Parallel to the need for *recognition and validation,* a sibling in Australia wrote, "Kids with illnesses or disabilities are not the only ones who suffer" (Livewire, 2011, Sibwire Siblings, Real Life Stories: "My Story--Trista Grinrod," para. 4).

Having fun with the affected brother or sister is another subtheme that was found in siblings' comments online. One 9 year old sibling said, "The good thing about my sister is that she plays with me" (Siblings Australia, 2011, Young Sibs: "What other kids say about being a sib," para. 6). Likewise, a 10 year old sibling stated, "She [her sister] can be lots of fun when she wants to be" (Siblings Australia, 2011, Young Sibs: "What other kids say about being a sib," para. 3).

Chapter VIII

SUMMARY, CONCLUSIONS, AND IMPLICATIONS

Summary

The aim of this study was to identify, describe and understand the experience of being a well school-age sibling of a child recovering from a traumatic medical injury. Using phenomenology as the method, the experience was explored with participants who were engaged in the phenomenon; data was collected and described using their words; themes and metathemes were identified; findings were analyzed and interpreted in relation to developmental theories, other research studies, and several literary and artistic sources in the culture. A deeper understanding of the meaning of what it is like to be a well school-age sibling of a child with a traumatic injury is presented here.

Conclusions

This phenomenological study uncovered four major themes regarding *the experience of being a well school-age sibling of a child with a traumatic injury*: the *compassion* felt and acted upon by the siblings, *the difficult nature* of the experience, and the components of *change* and of *constancy* that exist within this phenomenon. An array of sub-themes (totaling 14) was revealed within the four themes, some of which were feelings and emotions, and some of which were actions and experiences. Major sub-themes, many of which were confirmed in the literature, were: *sadness*; *difficulty* seeing the injured child, especially the child in *pain*; sense of *loss*; *closer*

sibling relationship, and *love* of the brother or sister; constancy of *sibling rivalry*; constancy of *school life*; and the willingness of the sibling to take on *tasks and responsibilities* within the family household. Three metathemes captured the essence of the experience for the siblings: this was an *emotional experience* for the siblings; there was *opportunity for growth* for the siblings, emotionally and socially; and there now exists *a different world* for the siblings than existed before the injury. Needs of the siblings focused on their desire to be included in the experience through *information* and *communication*, and the need for their sense of self to be *validated* and *recognized*, especially by adults and health care professionals. The cognitive, social, and emotional development of the school-age child shaped the experience for them in such a way that it was *concrete* and *present-focused*, rather than future focused. Expressions of the sibling experience were found in art, literature, and media-based resources, drawn from the lifeworld of children.

Strengths and Weaknesses of the Study

The study's aim was to identify, describe and understand the experience of being a well school-age sibling of a child recovering from a traumatic medical injury. Themes and subthemes were identified that described the essences of the experience for school-age siblings. An understanding of the phenomenon was realized through analysis and interpretation of the themes as related to widely accepted theories, comparison of the themes to other research study findings, and by seeking and finding examples of the same or similar themes in the popular culture

that constitutes the lifeworld of children. The findings in this study were consistent with Bowen's (1978) Family Systems theory, Piaget's (Piaget & Inhelder, 1963/1966; Piaget, 1974) theory of Intellectual Development of the Child, Erikson's (1950/1963) developmental theory and the Eight Ages of Man, and the concepts of identity development concerning sibling relationships put forth by Bank and Kahn (1982/1997). The findings provide a deeper understanding of the meaning of this experience in the lives of well school-age siblings. By accomplishing the aim of this study, this research has added to the body of knowledge for nursing.

This study focused exclusively on the siblings' perspective. Another strength of the study was that data were collected from siblings who were actually immersed in the phenomenon of interest at the time of the interviews. Each sibling shared his or her experience willingly and honestly. Munhall (2007) stated, "Meaning is found in the transaction between an individual and a situation . . ." (p. 162), so that going directly to the siblings for their perspective and experience was, indeed, calculated and fitting, and provided the best possible findings from which to derive understanding of the human experience.

The mix of siblings that participated was diverse in age and gender, age difference between the sibling and the index child, and racial and ethnic features. This diversity added to the strength of the study. Several types of traumatic injuries were represented in the medical diagnoses of the affected children, but some typical traumatic injuries of children were not represented. For example, there were no diagnoses of Burns or Near-drowning, which would have been desirable to include.

The siblings in this study were interviewed only one time. Although the original research design planned for 1-2 interviews with each child, practical and logistical considerations did not allow for more than 1 interview with each sibling. Interviewing each child on two separate occasions might have allowed for stronger engagement of the researcher with the siblings and more opportunity for member-checking. However, data saturation was achieved.

Another strength was the establishment of the trustworthiness of the research through the design and implementation of the research. All four research criteria for maintaining trustworthiness in qualitative research, set forth by Lincoln and Guba (1985), were met. These criteria included: credibility, transferability, dependability, and confirmability.

Van Manen's (1984; 1990) approach to go to the popular culture for examples of the experience in artistic and literary representations of thematic findings worked well. Many examples were found and illustrated so that the experience could be viewed through a different lens, thus adding to a fuller and richer understanding of the meaning of the experience in the lives of school age siblings.

Personal Reflections

Self-reflection is an essential component of phenomenology (Munhall, 2007), beginning early and continuing as an ongoing process throughout the research. Prior to any data collection or review of the literature, I began the self-reflection process and documented personal assumptions, biases, and beliefs. However, now

that data collection and data analysis are complete, and essences of the experience have been identified from the perspectives of the school-age siblings, further self-reflection has resulted in a change in my own beliefs. My personal beliefs have been changed and shaped by the perceptions of the siblings who were actually involved in the experience.

How beliefs changed.

My pre-study beliefs held that unrecognized needs, and possibly risk or threat of harm to the well-being of well siblings, existed within families experiencing the crisis of a child's traumatic injury. Since gathering and analyzing the data collected in this research study, my beliefs have changed regarding these risks to some extent. All of the siblings in the study demonstrated a remarkable sense of resilience regarding the family crisis they were experiencing. While family systems models allow for re-patterning of the family, my bias previously had been that well siblings may be negatively affected in future development and evolving family processes. This belief was stronger pre-research. Now, although I believe that this is still a *potential risk*, I expect that school age siblings can possess the resilience to navigate through the crisis in a more positive way and avoid serious consequences and harm to their well-being. Indeed, the experience may even support the foundation of a stronger and more fully developed sense of self-esteem as siblings take on new roles and tasks within the family.

In the same way, my pre-research belief held that siblings may experience feelings of sadness, guilt, anxiety, loneliness, and/or anger and resentment. Guilt and

anger may still occur in some siblings; however, I now believe that these emotions are less likely to be a real peril to this age group. None of the 7 siblings in this study spoke of such emotions. It is much more likely that school age siblings will experience sadness, the continued emotions of sibling rivalry toward the affected child, and a sense of loss and loneliness for both the affected brother and sister, as well as for the parents. When siblings receive active support from adults regarding such unresolved feelings and emotions, and when siblings are provided with the opportunity to freely express these feelings in positive ways, they are much less likely to be at risk for repercussions which can affect the siblings' self-esteem and psychosocial development. This need for adult support includes the need for clear and simple information from parents and healthcare workers, in keeping with their understanding and their desire for information.

I now believe that there are important developmental considerations inherent in the school-age level of development that have implications concerning this experience under study. Erikson (1950/1963) stated that the school age child develops a sense of industry versus inferiority; a sense of competence and good feeling about self is developed when new experiences are met with success. Moreover, the school age child's parents, along with other caring adults, are still the most significant people in their lives. There are opportunities in the experience for school-age siblings to take on new roles and tasks within the family unit, and thus, to develop self-esteem when the sibling receives positive feedback and reinforcement from adult authority figures regarding the contributions made to the family re-patterning and reorganization. This

unique opportunity can support and foster Erikson's developmental task of developing a good self-esteem. Therefore, it is my belief that the experience of having a brother or sister with a traumatic injury can be one with some *positive and serendipitous outcomes* for this age group.

These subtle but important changes in my beliefs evolved in response to listening to, reflecting upon, and systematically analyzing the siblings' experiences. My beliefs previously were drawn from evidence experienced anecdotally in the course of my nursing career. Through the phenomenological process, my previous assumptions and biases have been transformed into empirical beliefs now rooted in the data collected. It is important that the discovery of new knowledge influences previous beliefs and professional behaviors. The professional practice of nursing should be informed and shaped by *the best evidence available.* This study provides empirically collected and systematically analyzed evidence, which can influence the foundation of professional nursing practice.

Other reflections.

This doctoral education has been a universe of experiences centered on learning the research process. Along the way, so many unforeseen and unexpected events have altered my course and changed my perspectives on education, research, and relationships. It has been the foundation of tremendous professional growth and personal accomplishment. I liken myself to a sojourner, who may enjoy the brief stay at a place of comfort, but looks forward to moving on to the next settlement down the road and over the next challenging hill.

The research process, if done well, is difficult and rigorous. Although the researcher must reach out to many other professionals and key people within the realm of the experience, a large part of the researcher's work is done independently. It takes a motivated and self-directed researcher to follow the research trail to completion. With qualitative research, and most especially with phenomenology, the researcher truly becomes an instrument of the research process (Rew, Bechtel, & Sapp, 1993).

I was impressed by the grace and poise demonstrated by the 7 siblings that participated in this study. Although only school-age, their sense of maturity at times seemed to me to be beyond their developmental level. The compassion they showed for their brothers and sisters, as well as for other children they encountered at the hospital, was amazing. In fact, they coped better than I had expected to find, and expressed no anger or strong resentment. Constancy of routines and contact with other loving adults, such as grandparents, seem to be part of the "tool kit" that supported the school-age child through this experience and fostered their coping skills. Nurses need to consider this when planning care for families, as this has significance for nursing practice. The needs of these siblings seem to be largely overlooked by practicing health professionals.

Finally, the importance of the developmental level—and understanding it—is fundamental to understanding the siblings' responses to the experience. Their developmental level is intimately connected to their understanding and response to

the experience as they live through the early weeks and months of this unexpected life event.

Personal change.

My new mantra is: *Think, Reflect, Ponder*. I had these words painted on the walls of my office, and repeat them to myself and students frequently. Why is this? It was my experience in this research process that when the words of the siblings were read and re-read, and time was spent dwelling with the data, there was an opportunity created to discover new knowledge in the words. I learned to become immersed in the data and not to be too quick to make assumptions. Munhall's (1993) fifth pattern of knowing, that is, of *unknowing,* is difficult, yet extremely valuable to the researcher's ability to remain open to the experience and to know the experience in a way that he/she might never have been able to otherwise do. Additionally, besides reading and re-reading the transcriptions, there is value in going back and listening to the recorded interviews. There is something about hearing the words and the tone, inflection, and emphasis of the siblings' spoken words, that makes for a richer understanding of the intent of the words. I re-listened and re-read several times—both must be done.

Interviewing children from 8 to 12 years of age for a formal study was different from the informal conversations I had with similar children over the years. The differences were subtle, but real. The siblings knew that what they said in the interviews was being recorded and importance was being placed on their experience. It is my intuitive observation that this imparted a sense of importance and seriousness to the purpose of the conversations. Indeed, some siblings spoke of their delight in

being asked about their experience. What they said "counted" and someone was paying attention! No sibling in the study asked to end the interview early or to be returned to their parent before the end of the interview. It is my belief that they wanted to be heard and spoke honestly and forthrightly.

I am honored to have been let into the lives of such a vulnerable group of children and families, and am grateful for the experience.

Reflections on Dissertation: One Nurse's Experience

The journey is long
And lonely at times.
Moments of happiness
Satisfaction . . . surprise.
But mostly hard work.
Details . . . and thought.
Think . . . Ponder . . . Reflect.
My new mantra.
My new compass.
My new pattern,
Everlasting,
Never ending . . . so it seems.

A delight when talking with the wonderful children,
The fantastic siblings of injured kids.

The honor is all mine.
To listen to them,
To hear their words,
Understand their thoughts,
Discover their experience.
They share this with *me* . . .
So I can share their experience with others.
To them I am thankful,
Of them I am awed.
Such feelings and thoughts
In the minds of young children.
Who'd have thought it?

Who'd have known?
No one . . . unless asked,
Unless sought out.
We are truly blessed to
Be invited into the
Phenomenon that is
The Experience of Well School-Age Siblings of Traumatically Injured Children.
To catch a glimpse of what it is like . . .
To see a bit of that moment in time for them. (Bugel, Reflexive log, 2010)

Implications for Nursing Practice

The rich description of the experiences of these siblings, and the themes that emerged, provide a deeper understanding of the experiences of well school-age siblings of children with traumatic injuries, thereby adding to the body of knowledge for nursing. What are the specific implications that now exist for nursing?

To answer this important question, evidence-based *Recommendations for Nursing Practice* regarding school-age siblings were developed. They are rooted in the research findings, based on empirical data, and took consideration of the self-stated needs and recommendations of the siblings. They are:

1. Discuss the "sibling experience" with parents regarding the research-based responses of siblings, and alert parents to the needs of siblings.

    Note: Early in the admission process, the nurse can make the parents aware of research-based findings regarding school-age siblings, including: typical feelings of siblings, the need for recognition and validation, and the need for information, etc.

2. Assess the needs of siblings as part of the overall family assessment, especially related to learning needs.

   Note: The nurse should discuss with parents: the school-age sibling's needs, what they have been told, how much they will be involved, how often they will visit, what would be acceptable to talk to the sibling about, what would be acceptable to teach siblings regarding the injury, etc.

3. Greet siblings and address each sibling by his or her given name.

   Note: Nurses should always learn the sibling's name and speak to the sibling in a friendly manner by name when they are visiting. At a minimum, nurses should say "hi" and ask the sibling how he or she is doing that day.

4. Whenever possible, include siblings in fun and recreational activities in which they can participate with their brothers or sisters.

   Note: The nurse can help structure fun activities and/or initiate the sibling and the child going to Recreation therapy together. Nurses may introduce the sibling to the Recreation therapy staff and/or the Child Life staff.

5. Ask siblings if they have questions they would like answered, and keep siblings informed in an age-appropriate way.

Note: With the permission of the parents, the nurse may encourage and answer questions for the siblings in accordance with their developmental level and interest.

6. Allow siblings opportunities to express themselves concerning their experience.

   Note: When appropriate, allow siblings to speak candidly about their experience. Inform parents (and with parental permission, the sibling) about organized sibling support groups and activities available.

7. Speak with siblings regarding sibling rivalry; acknowledge that they may have feelings of jealousy.

   Note: Although continued sibling rivalry is expected, nurses can let siblings know that we understand they might be jealous of all of the attention that the brothers or sisters are receiving and that it is normal for them to feel that way.

8. Encourage parents to spend some alone time with the sibling when possible, outside of the hospital experience.

   Note: One aim of parenting is to lessen rivalry whether with well or ill children for better developmental outcomes. By spending alone time with the sibling, rivalry may be minimized.

Recommendations for Future Research

A hermeneutic approach to the findings of this study triggers the following questions: What do these findings mean in the overall life of the sibling? What is the meaning of this experience to the sibling as he or she goes forward into adolescence and adulthood? What significance shall the sibling assign to this poignant experience in his or her life in the future? These questions and answers were not the focus of this study, but are none-the-less very relevant questions. Therefore, further study is warranted.

There is a need for a follow-up longitudinal study to examine the experience and reflections of these siblings as they move on to adolescence. How may life continue to change? Will the themes identified in the school-age years continue to be significant? Will there be a change in the quality of life for these siblings? Will anger, resentment, or guilty feelings occur? Will the sibling relationship continue to become closer, or become strained and weaken? Looking even further ahead, will the compassion shown by these siblings so early in life result in the siblings becoming compassionate adults?

Another recommendation is to design and implement a quantitative study that examines the identified themes, such as *sadness* and *need for validation* (among others) and study their relationship. Are they correlated? How are they associated? What other variables affect these?

Finally, in future studies of siblings of children with traumatic injuries, a recommendation is to include additional types of traumatic injuries which may be more visibly recognizable, such as the diagnoses of burns and amputations.

A Final Thought

Siblings by mary jo bugel

And when I come to visit with my sister,
The sadness in my heart is sharply felt.
To see her there so injured and so fragile,
I reach out, yet I know not how to help.
We have some fun when we are both together.
A smile, a touch, a word . . . we share so close.
I want to know what happens for her now, then.
But no one tells me what I need the most.
I spend some time with her inside her room there.
A nurse walks by and briefly looks my way.
Did she see me here, or know that I have questions?
Can I help? Or watch? And can my sister play?
And so I carry on with school, and friends,
I help around the house as best I can.
My parents are not home like once they were.

I miss them, but I try to understand.

I must admit that there are times, I think

I should have been the one who had the fall.

Receiving many gifts and many presents,

And time, and love, and care, from one and all.

But in the end, I really love my sister.

I see the pain that now is in her world.

I want to help, but then, again I realize,

I want to help, but I am just a girl.

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Appendix A

[1]Methodological Outline for Doing Phenomenology

A. Turning to the Nature of Lived Experience

1. Orienting to the phenomenon

2. Formulating the phenomenological question

3. Explicating assumptions and preunderstandings

B. Existential Investigation

4. Exploring the phenomenon: generating data

   4.1 Using personal experience as starting-point
   4.2 Tracing etymological sources
   4.3 Searching idiomatic phrases
   4.4 Obtaining experiential descriptions from subjects
   4.5 Locating experiential descriptions in literature, art, etc.

5. Consulting phenomenological literature

C. Phenomenological Reflection

6. Conducting thematic analysis
   6.1.1 Uncovering thematic aspects in lifeworld descriptions
   6.1.2 Isolating thematic statements
   6.1.3 Composing linguistic transformations
   6.2 Gleaning thematic descriptions from artistic sources

7. Determining essential themes

D. Phenomenological Writing

8. Attending to the speaking of language

9. Varying examples

10. Writing

11. Rewriting (A) to (D), etc.

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[1] Van Manen, M. (1984). *"Doing" phenomenological research and writing: An introduction* (Monograph No. 7, p. 5). Alberta, Canada: University of Alberta.

Appendix B

Major Themes & Subthemes; Metathemes

Major themes & corresponding subthemes:

1. Compassion
    a. *Sadness*
    b. *Empathy*
    c. *Altruism*
2. A Difficult Experience
    a. *Seeing the injured child*
    b. *Pain*
    c. *Loss*
3. Changes
    a. *Change in the sibling relationship*
    b. *Involvement of other caring adults*
    c. *Sleep patterns*
    d. *Daily routines*
    e. *Other differences*
4. *Constants*
    a. *Sibling rivalry*
    b. *School life*
    c. *Still having fun*

Metathemes:

1. An Emotional Experience
2. Opportunity for Growth
3. A Different World

Appendix C

Siblings' Needs, Advice, & Idea

1. Needs

    a. *Recognition & validation*
    b. *Information & communication*

2. Advice

    a. *Have fun*
    b. *Know that it is difficult*
    c. *Find other activities to do*
    d. *Include siblings in activities*
    e. *Consider using a children's hospital*

3. Idea: *Sibling Lounge*

Appendix D

Parent Consent Form

Researcher's Affiliation
The researcher, Mary Jo Bugel, M.A., R.N., is a doctoral student at Seton Hall University College of Nursing in the Department of Behavioral Sciences, Community and Health Systems. She is doing a study called, *"The Experience of Being a Well School-Age Sibling of a Child who has a Traumatic Injury."*

Purpose of the Study
The aim of this research study is to describe and understand what it is like to be a well, school-age sibling (from 8-12 years of age) who has a brother or sister with a traumatic injury going through rehabilitation in a hospital. The researcher wants to learn what this experience is like for the sibling, from the sibling's point-of-view.

Procedure
The researcher will meet with the sibling to talk to him/her at least 1 time, but it may be 2 times. The interviews will be simple, audio-recorded conversations between the researcher and the sibling. They will be done at a time that is convenient for the parent and sibling. They will take place in a private office at Children's Specialized Hospital on the patient unit. The parent will be told the exact room location before the interview. The door to the room will remain partially open. The parent may inspect this room before the interview if he/she wants. Only the researcher and the sibling will be in the room during the interview.

Duration of the Study
Each interview will take from 25-60 minutes. The interviews will be done over a 1-2 week period of time.

Interviews
The researcher will do the interviews, and the conversations will be audio-recorded. The sibling will be asked broad questions like, "Do you remember when you found out about your brother's (or sister's) accident? Can you tell me about it? Has anything changed for you since then?" The sibling will be encouraged to talk about the experience and what is like *for him/her* using his/her own words.

Audio Recording
Audio-recording the interviews will help keep the research accurate and high-quality. In other words, the recordings will help make sure that all records of the talks are correct and can be analyzed on correct data. The recordings will allow the researcher to review the interviews for study purposes at a later time. The sibling will not be identified on any audio-recording. Code numbers and a fictitious name (rather than the real name) will be used when speaking to the sibling. The audio-recordings will

be written out exactly word-for-word by the researcher. The written out words of the interviews will be stored as a paper copy and as an electronic file on a USB memory key. They will be kept in a secure locked file in the home of the researcher. The researcher will have the only key to the file. No one except the researcher and her faculty advisor have access to this data. The parent will not have access to this data. The parent will be asked to sign a separate section on this form to document his/her consent to have the sibling's interviews audio-recorded.

Art Work

If the sibling is timid about starting to talk and shows an interest in drawing, he/she may choose to do a drawing as an "ice-breaking" or "warm-up" activity. The sibling will keep his/her drawing. The researcher will have some art materials on hand. The researcher will ask the sibling to draw a picture with crayons and markers. The sibling may draw anything he/she would like. The researcher will ask the sibling to tell her about the drawing. This introductory activity is expected to help the sibling get more familiar with the researcher, feel more comfortable, and be able to start talking about his/her experience. The sibling will keep the drawing, and no copy of the drawing will be kept by the researcher.

Voluntary Nature of the Participation

This study is completely voluntary. The sibling is free to withdraw from the study at any time with no penalty. He/she may stop an interview at any time, even if the parent has given permission for him/her to participate. The sibling does not have to answer any question that he/she does not want to answer. At the beginning of each interview, the sibling will be reminded of his/her freedom to stop participating. Dropping out of the study at any time will involve no penalty or loss of benefits for the sibling, the family, or the injured child. The care of the hospitalized child will not be affected.

Anonymity

The researcher guarantees that the siblings in this study will not be identified by name. There will be no way for anyone to identify the siblings from the interview data. All data will be coded using a numbering system. No real names or any other identifiers will ever be used in any reports of the study. The name and location of the hospital will not be identified in any of the reports of the findings of the study.

Confidentiality

All materials collected during this study and records of the data will be confidential. All information that is obtained from the siblings in this study will be stored electronically on a USB memory key, and kept in a locked file in the researcher's home office. All audio-recordings will be kept in the same locked file. Code numbers and fictitious names will be used to match the audio-recordings, paper transcriptions, and electronic files. No siblings will be identified by name on any research documents. A single master list of the actual names of children who participated in the study, with their unique code numbers and fictitious names, must be created for

future reference by the researcher in the event that any unforeseen event occurs and parents need to be contacted. The single master list will be stored in a locked drawer entirely separate from other stored research material. Only the researcher will have knowledge of the locked storage site and access to it. However, if a child says that someone is harming or hurting him/her in some way, the researcher is mandated to report suspected child abuse to the proper authorities.

Records
Only the researcher and her faculty advisor have access to the confidential research records. All results and findings of this study will be used for research purposes only. A report of aggregate research findings, which may include anonymous verbatim (word-for-word) quotations of words spoken by a sibling, will be made available to the public through scholarly presentations at professional conferences and by publication in professional journals and literature. Reports will never use individual identifiers and confidentiality of all data is guaranteed. Three years after the completion of the study, all paper and audio-recording files will be destroyed and discarded by the researcher.

Risks or Discomforts
Participation in this study poses no foreseeable risk of physical, social, legal or economic harm. There is, however, a possibility of potential risk related to emotional discomfort. Interviews may remind the sibling of difficult issues related to the experience that he/she will talk about. While not expected, some children may become bothered or upset. If this happens, the researcher will stop the interview and stay with sibling until the sibling is calm and feeling better. In the event any child is unable to calm him/herself, a Clinical Psychologist from the hospital is on-call if needed to assist with any extreme reactions. At any time, if the parent notices that the sibling is having study related issues, the parent should call the sibling's Primary Care Provider and/or the Director of Clinical Psychology at CSH (who may be contacted through the Psychology Department at CSH). Additionally, a List of Community Mental Health Providers is being given to the parent along with a copy of this Parent Consent Form.

Benefits
There is no expected direct benefit for the sibling participants of this study. However, participating in this study has the potential to increase knowledge about what this experience is like for school-age siblings. Information learned as a result of this study may be used in the future to help children and families going through a similar experience. When this study is completed, the researcher will send a summary of the aggregate findings to the parents of participants if they would like.

Compensation
There is no compensation or payment to the siblings participating in this study. However, when the sibling is finished participating in the study, and if the parent

would like, the parent may choose a book to be given to the sibling. The researcher will have a collection of developmentally appropriate children's books on hand, from which the parent may select. This book is offered as a small token of the researcher's appreciation and thanks to the sibling.

Contact Information

The researcher for this study is: Mary Jo Bugel, M.A., Ph.D.(c), R.N. If the parent has any questions about the study, the researcher can be contacted at 973-761-7949 by leaving a message. The parent will receive a return telephone call within a few days. Or, the researcher may be contacted by e-mail at Bugelmaj@shu.edu . In addition, the faculty advisor, Dr. Judith Lothian, R.N., Ph.D., Dissertation Committee Chairperson, may be contacted at 973-761-9273, or by e-mail at Lothiaju@shu.edu . If there are any questions regarding the sibling's rights as a research participant, or the parent feel there has been a research-related injury, the parent should contact the Director of the Institutional Review Board at Seton Hall University, Dr. Mary Ruzicka, Ph.D., at 973-313-6314.

Parent Consent for Child to Participate in the Study

I have read (or have had read to me) the contents of this Parent Consent Form and have been encouraged to ask questions. I have received answers to my questions and fully understand what is expected of me and my child in this research study. I give my consent for my child, _____, to participate in this study by Mary Jo Bugel called, "*The Experience of Being a Well School-age Sibling of a Child who has a Traumatic Injury.*" Mary Jo Bugel has my consent to approach my child and discuss his/her participation in this study and for my child to be interviewed by her. Once I have given my consent, I understand that my child must also give his/her assent to participate in this study. I have received (or will receive) a copy of this Parent Consent Form and the Child Assent Form for my records and future reference. I will also receive a List of Community Mental Health Providers.

_____
(Print-Name of parent or legal guardian)

_____ _____
(Signature of parent or legal guardian) (Date)

Parent Consent for Child to be Audio-Recorded

I give my consent for my child, _____, to have his/her interviews with Mary Jo Bugel recorded on a digital audio-recorder as part of the research study entitled, "*The Experience of Being a Well School-age Sibling of a Child who has a Traumatic Injury.*"

_____
(Print-Name of parent or legal guardian)

_____ _____
(Signature of parent or legal guardian) (Date)

Appendix E

Child Assent Form

My name is _____. I am _____ years old.

I want to help Mrs. Bugel with her study. This study will try to learn what it is like to be a brother or sister of a child who was hurt in an accident.

I will talk alone with Mrs. Bugel. We will meet one or two times. Each time, it will be for less than an hour.

Mrs. Bugel will not tell anyone what I say using my name. Her teacher can go over what we say, but she will not know my name. When Mrs. Bugel writes her report, my name will never be used.

My Mom or Dad will not know what I say to Mrs. Bugel. But if I tell Mrs. Bugel that someone is hurting me in some way, she will have to tell another adult.

No one is making me do this. If I want, I can stop at any time. Nothing else will happen if I want to stop. It will be OK. Even my Mom or Dad cannot make me do this.

The talks I have with Mrs. Bugel will help nurses learn more about what it is like to have a brother or sister with an injury.

If I have a question about this study, I can ask Mrs. Bugel or my Mom or Dad. Mrs. Bugel has not promised me any special gift to be in the study.

_____ _____

(place to sign your name) (Date)

I will let Mrs. Bugel audio-record our talks. No one else will listen to the talks. Even my Mom or Dad cannot listen to the recordings of our talks.

_____ _____

(place to sign your name) (Date)

Parent Section:

I know that my child freely assented to be a sibling participant in this study. My child and I have been given a copy of this Child Assent Form.

_____ _____

(Signature of parent or guardian) (Date)

[Note: Images are from MicroSoft Office Clip Art (Version 2009).]