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The Experience Of Family Resilience Through Severe Traumatic Brain Injury

Shanda C.E. Hochstetler

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THE EXPERIENCE OF FAMILY RESILIENCE THROUGH SEVERE TRAUMATIC BRAIN INJURY

by

Shanda Charlene Epp Hochstetler
Bachelor of Arts in Social Work, Goshen College, 2006

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This thesis, submitted by Shanda C.E. Hochstetler in partial fulfillment of the requirements for the Degree of Master of Social Work from the University of North Dakota, has been read by the Faculty Advisory Committee under whom the work has been done and is hereby approved.

Dr. Andrew Quinn, Chairperson

Dr. Amy Phillips, Committee Member

Dr. Randy Nedegaard, Committee Member

This thesis meets the standards for appearance, conforms to the style and format requirements of the Graduate School of the University of North Dakota, and is hereby approved.

Wayne E Swisher

Dr. Wayne Swisher, Dean of the Graduate School

May 2, 2013

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ACKNOWLEDGMENTS

I am, first and foremost, deeply grateful for the generosity and kindness of the families who participated in this study. Thank you for sharing your journey with me. Thank you for your bravery and your welcome, for your energy and your honesty, for your seemingly unending dedication to hope and healing.

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To My Parents—Les & Gayle

To My Sisters—Carmen, Kim, Tiffany, Kayla, Jonae, & Brittany

& Most of all,
To My Brother—Landon

ABSTRACT

Traumatic brain injury (TBI) is a leading cause of death and disability. Of these injuries, severe TBI (STBI) causes the most profound and long-term disabilities. The experience of STBI has been shown to affect the entire family. Social work professionals need to be aware of the experience of STBI and must be prepared support families through this trauma. The objective in this research was to explore how families experience STBI through the lens of family resilience. A mixed method approach, focused predominantly on the qualitative, was used to draw out the experience of five families wherein a child sustained an STBI.

The research discovered through data analysis of family interviews eight categories of the family experience of STBI. Families experience STBI as: a long road and a rollercoaster of emotions wherein isolation, exhaustion, grief intermingle, and wherein navigating the medical system and wrestling with unknowns are constant demands. The research revealed eleven categories of how families experience resilience through STBI. Families experienced resilience by accepting the reality of the injury while also acknowledging their grief of loss, allowing family members to react uniquely, incorporating some normal back into their family life, laughing together, believe and investing in recovery, celebrating small victories, believing in who s/he was, connecting with others, receiving support from others, engaging in spirituality, and seeking meaning beyond existence. In addition, families specifically wanted social workers to know: how

grateful they were for their help, how important hope was for families, how helpful it was when the whole family received care, and how valuable clear information and direct resources were.

These findings were supported by the quantitative data, by participant feedback, and by comparison to family resilience framework (Walsh, 1998). These discoveries can better prepare social work practitioners to identify and build on family resilience as families move through the unique trauma of STBI.

CHAPTER I

INTRODUCTION

This thesis is a mixed method study, with emphasis on the qualitative, exploring severe traumatic brain injury (STBI) and family resilience through the stories of five families who have had a child family member sustain a severe traumatic brain injury. One of these families is my own. The purpose of this study is to examine the experience of STBI through the lens of family resilience by exploring how families experience STBI and how resilience emerges within that experience.

Researcher's Personal Framework

Shortly after I began my graduate studies in social work, my 16-year-old brother was in a pedestrian-vehicle accident near my family's home. My brother sustained an STBI and I put my studies on hold as we, as a family, were thrown into the long journey of recovery and of reconstructing our very existence. This experience has shaped, guided, and inspired this thesis throughout. I am both an observer and a co-participant in this exploratory study. I have strived to develop a study that contributes to the social work profession, exploring family well-being through what I know personally to be a deeply painful experience. Without acknowledgement of my identity as a member of the population I am studying, this research would lack integrity and would fail to capture the fullness of this project.

Research Objective

The objective in this research is to explore how families experience resilience through STBI. A mixed method approach that focuses predominantly on the qualitative is used to draw out the stories of families in a way that invites the reader to begin to know STBI and the experience of family resilience in the midst of this particular trauma. The research questions explored through this study are:

1) How have families experienced the journey of a child family member sustaining a severe traumatic brain injury?

2) What has resilience looked like for these families and what fostered family resilience during their journey?

As a result of analyzing the data that emerged on these two research questions, feedback for social workers along with implications of practice will be discussed.

Chapter II of this thesis will review the literature on STBI and on family resilience demonstrating a need for this project. Chapter III describes the methodology used to complete in this study. Chapter IV outlines the categories that emerged in reference to the two research questions and the feedback participants shared for social workers. In Chapter V, the results are further explored through discussion, concluding remarks, personal reflection, and guidance for future research.

CHAPTER II

LITERATURE REVIEW

In building this exploratory research study, severe traumatic brain injury (STBI) and family resilience were examined throughout the literature. This chapter discusses STBI and family resilience in depth, exploring the research within social work and in related fields, considering the implications of the research, and identifying the gaps within the literature that led to the design of this current study.

Severe Traumatic Brain Injury

Defined as an "alteration in brain function…caused by external force," traumatic brain injury (TBI) is significant public health concern and a leading cause of death and disability (Brain Injury Association of America [BIAA], 2012; Hyder, Wunderlich, Puvanachandra, Gururaj, & Kobusingye, 2007). Each year in the United States, 1.7 million people sustain a TBI and, of these individuals, approximately 52,000 die as a result of the injury (Faul, Xu, Wald, Coronado, & Dellinger, 2010). Brain injuries are most frequently the result of injuries from vehicle accidents, falls, collisions, and violence (BIAA, 2012; Hyder et al., 2007). Those who survive TBI have a high probability of facing ongoing disability. Many challenges lie ahead as individuals work to recover from a TBI. A study of TBI survivors (N=2,118) who were hospitalized showed 43% had long-term, TBI-related disability as measured approximately 12 months after hospital discharge (Selassie, Zaloshnja, Langlois, Miller, Jones, & Steiner, 2008). TBI is a serious public health concern and it carries with it long-term effects.

Traumatic brain injuries are categorized as mild, moderate or severe depending on the extent and type of damage. Measures most commonly utilized to determine severity of injury are the Glascow Coma Scale (GCS), measured loss of consciousness, measured posttraumatic amnesia, and neuro-imaging such as a computerized tomography (CT scan) (Kraus, 1995). The GCS is a global neurological measure that evaluates response to stimuli. A GCS score of 3-8 (out of a possible 15) designates an injury as severe (Bond, Draeger, Mandleco, & Donnelly, 2003). Individuals with STBI will typically experience loss of or impaired consciousness for an extended period of time—from a few hours to weeks (Zasler, 2007). In this project, the term severe traumatic brain injury will be used to include injuries wherein the early injury severity of TBI was indexed as severe by attending medical staff.

STBI is less common than mild or moderate TBI and has greater long-term effects. Only an estimated 10% of sustained brain injuries will be classified as severe (Bond et al., 2003). The severity of injury has been shown to directly correlate with the individual's long-term outcome (Thurman, Alverson, Dunn, Guerrero, & Sniezek, 1999). An STBI commonly leads to both long- and short-term disabilities that affect development and functioning socially, cognitively, physically, behaviorally, and emotionally (Roscigno & Swanson, 2011). While STBI is less common than mild or moderate TBI, it carries with it more profound and longer-term disabilities and life challenges.

As patients regain consciousness, STBI leaves individuals with an uncertain future and a long road to recovery. Those sustaining an STBI struggle to re-learn many of the basic physical, cognitive, and mental skills they performed without difficulty previous to injury, including walking, talking, basic muscle movements, memory recall, and social skills (Thurman et al., 1999). Recovery for the injured individual typically includes an extended period of time in the hospital, followed by in-patient acute rehabilitation. Individuals then face decisions about long-term care and long-term rehabilitation options. These decisions are heavily influenced by insurance, funds available, and the ability of the injured individual to participate in the decision-making process. In his extensive literature review on families with sustained head injuries, Brooks writes “severe head injury is forever, though few, if any, family members realize this in the early stages” (1991, p. 181).

For those recovering from STBI, there is a significant lack of support and lack of understanding within society and within professional fields. Roscigno’s (2008) in-depth study of children’s and parent’s experience of moderate to severe TBI demonstrated that both children and their parents experienced increased stress due to unsupportive behaviors of society including from professional support persons and informal support persons (N= 39 children, 42 parents).

STBI is a serious and ongoing health concern. Those individuals who have survived an STBI will face many challenges ahead as they deal with the sudden onset of disability, loss of their previous freedoms, an ambiguous outlook for recovery, and a world that is often not prepared to support them through these changes.

Family Experience of Severe Traumatic Brain Injury

Though the individual alone sustains the physical injury, STBI is experienced by the entire family. For the purposes of this paper, family is a self-defined group of two or more individuals who are dependent upon each other for support—emotionally, physically, economically, spiritually, and developmentally (Black & Lobo, 2008). In review of the literature on family experiences of STBI, this section discusses the shock and crisis of the injury, the confusion of roles, grief, and long-term care.

An STBI causes exceptional disruption for the injured individual and for the whole family. Life for the family must be re-imagined and reconstructed as the family deals with the multi-dimensional impact of the brain injury (Kosciulek & McCubbin, 1993). The entire family is irreversibly changed as they move through the trauma and deal with the long-term stress that comes with STBI (Josie et al., 2008; Perlesz, Kinsella, & Crowe, 1999; Stancin, Wade, Walz, Yeates, & Taylor, 2008).

Initially families of survivors of STBI must deal with the shock and crisis of sudden injury. Individuals with an STBI are comatose for an extended time in a hospital intensive care unit (ICU) setting. Families are expected to learn complex medical terminology and care procedures. Critical medical decisions must be made quickly. Support services must be accessed. Amidst this, families report a lack of information and a lack of support as they navigate these new challenges (Paterson, Kieloch, & Gmiterek, 2001; Serio, Kreutzer, & Gervasio, 1995). Roscigno and Swanson's (2011) interviews with 42 parents of children with sustained moderate or severe TBI reveal four themes common in their experiences: 1) grateful to still have my child; 2) grieving for the child I knew; 3) running on nerves; and 4) grappling to get what my child and family need. In a study exploring the experience of the families of eight individuals with moderate to severe TBI being informed that their loved one has TBI, Lefebvre and Levert (2006) discovered that families report initial shock, uncertainty, and lack of information in the disclosure of TBI.

The unknowns and restricted knowledge makes the waiting even more difficult for family members. Jumisko, Lexell, and Soderberg (2007) revealed a common feeling among families of individuals with moderate to severe TBI in the aftermath of the injury was a sense of "fighting not to lose their foothold." This study of eight family members captured the willingness of family to fight out of a sense of love and hope even while feeling unsupported in their own suffering and grief. Similarly, Bond, et al. (2003) found four common themes in what families of patients with an STBI in the ICU identified as needs. The themes were: 1) need to know, 2) need for consistent information, 3) need for involvement in care, and 4) need to make sense of the experience. During the immediate days following injury, families are in a state of grief and shock as they struggle to access clear information, to understand the nature of injury, and to cope with the unknowns.

As survivors with STBI move out of the hospital and into rehabilitation settings, families move from the crisis of the accident to a confusing space where grief mingles with hope, where questions of survival continue to be complex, and where the unknowns remain overwhelming. Roscigno and Swanson's study (2011) identified the social challenges of dealing with the onset of disability compacted by a society that is neither accepting nor understanding of TBI. An individual with an STBI is often fully dependent on the family to be their care giver, advocate, medical case worker, emotional support, rehabilitation expert, and cheerleader, all while still being expected to fill their family, community, and employment roles (Brooks, 1991; Jumisko et al., 2007; Roscigno & Swanson, 2011).

Families grieve the loss of the family member they once had and, at the same time, must struggle to find energy for the work of long-term care and recovery. Children with an STBI will be in need of intensive care giving, the responsibility for which often falls on the family. Collings (2008) explores the non-linear, nonfinite nature of this particular grief process for parents of brain-injured children in five families. These parents are acutely aware of the loss of the expected, "normal" lifespan for their child, yet find themselves without the support of a clear grief pattern such as happens when a child dies. Kruetzer, Kolakowsky-Hayner, Demm, and Meade (2002), in developing an intervention modality for families after TBI, insist that one guiding tenet to this work is recognizing that family members experience a longing for their family's pre-injury life to return. This process of grieving and coping with an STBI significantly impacts the family, as a unit.

The care and recovery of a family member with an STBI continues long-term. Families moving through STBI face grim or, perhaps worse, unknown prognosis for recovery. These unknowns persist indefinitely (Bond et al., 2003; Duff, 2002). Families of individuals with an STBI have demonstrated long-term lower family functioning and greater anxiety following STBI (Degeneffe, 2001). Curtiss, Klemz, & Vanderploeg (2000) studied the spouses of 20 individuals with brain injury. While they included all levels of severity, the mean initial GCS score of participants was 5.4 (with a range of 3-13) indicating a high level of injury severity in the sample. Results showed 60% of these families identified considerable, disruptive changes in family structure following TBI.

Perlesz, Kinsella, and Crowe's study (1999) compiled 37 studies of family outcomes following TBI. These studies demonstrate overwhelmingly that brain injury affects the psychosocial wellness of each person in the family and that TBI has a profound effect on the family unit. Likewise, Brooks (1991) discusses a wealth of longitudinal studies exploring family experiences of TBI from onset of injury to ten years post-injury finding with certainty that family stress and burden continue long-term. Jumisko et al. (2007) concluded from their study that professionals must be attentive to the ongoing care of the family and their grieving process.

Social Work Attention to STBI

Within social work research and practice, little attention has been paid to STBI. A search of "severe traumatic brain injury" within Social Work Abstracts, the leading social work research database covering 850 social work and human services journals, turned up just seven articles. Studies from medical and psychology fields dominate the research on family experiences of STBI. Furthermore, studies that focus on TBI that do exist within social work research have concentrated on mild or moderate brain injuries or have included all levels of severity. Additionally these studies have predominantly examined the experience from a caregiver stress point of view and do not attempt to gather the experience of the family as a unit, nor the experience of positive coping.

Research studies, by and large, have been conducted through a medical lens. Of the articles and studies reviewed within this section only three were written from a social work perspective. The remaining studies were completed within the fields of nursing, medical psychology, medical rehabilitation, neuropsychology, neurology, and medicine.

Within the literature, longitudinal studies showed stress and burden on the family, yet these studies did little to explore families who adjust and cope well (Perlesz et al., 1999). This suggests a need for increased research focused on resilience and on the ability of families to move toward positive healing rather than a narrow focus on stress and burden. More study is needed to examine the true scope of the family experience of STBI.

Family Resilience

The concept that humans have the power to cope in the face of adversity has long been a cornerstone of social work theory and practice as evidenced by the profession's commitment to a strengths-based perspective and to the person-in-environment approach (National Association of Social Workers [NASW], 2008). Though not always articulated as such, this concept is resilience. Resilience is the process of facing adversity and not only overcoming, but also emerging with increased strength and resources (Walsh, 2003). Resilience includes the understanding of risk as a situation or event that could potentially cause damage to a person's well-being. Resilience is a process of positive growth in response to this risk. More than just toughing it out, resilience is actively facing the struggle and working through it. Similarly, family resilience is the process of a family system being confronted with a risk, crisis or stressor and overcoming, adapting, and emerging as a more strengthened unit (Patterson, 2002).

During the past three decades, social science fields have moved from a focus on deficiencies and deficits toward a more person-centered, strengths-based approach (Patterson, 2002). Previous to this shift, it was accepted that trauma irreparably damaged individuals. It was understood that adverse situations negatively and irreversibly affect people's ability to survive and thrive. As mental health professions moved away from focusing on damage, research started to examine situations where adversity was overcome, where humans emerged from trauma with increased strength, where resilience was evident (Walsh, 2003).

The specific understanding and study of family resilience, within social work and within related fields, began by examining resilience within individuals facing trauma, stress, or adverse situations and then extending that understanding to the family system (Black & Lobo, 2008). The first studies to begin addressing resiliency were studies of resilient children. A pivotal study by Kaufman and Zigler (1987) discovered that most abused children, contrary to common assumptions, do not become abusers. Two thirds of these children, despite growing up in adverse situations, were able to overcome their trauma and become healthy parents. Building on this, Werner (1993) studied the experience of 700 children growing up in poverty in Hawaii. In his study, one third of the children who had experienced poverty in their childhood overcame the obstacles and went on to have successful lives as measured several times throughout their adulthood. Corroborating these findings were similar studies of people experiencing poverty, maltreatment, violence, chronic illness and catastrophic life events (Black & Lobo, 2008; Luthar, Cicchetti, & Becker, 2000). These studies largely focused on protective factors and personal traits that existed within the character of children who functioned positively following adverse experiences.

As studies grew, they focused on character traits with few studies attending to the role of relationships in building resilience (Walsh, 1998). However Werner's study revealed the effect of a significant relationship in the child's life as part of their resilience

(Simon, Murphy, & Smith, 2005; Werner, 1993). The presence of a significant relationship showed a positive correlation to resilience. This idea pointed to the need for further understanding of connectedness as related to resilience. While early studies focused on individual strengths and hardiness as a personal characteristic, it soon became evident that interconnectedness was a significant factor in resilience and the concept of resilience as a process and the concept of family resilience began to emerge.

Resilience came to be understood as a process involving multiple factors, which foster or inhibit the process of resilience, and less about individual characteristics that one inherently does or does not possess. In early studies, the family unit was viewed as part of the trauma, part of what needed to be overcome. However, as research in resilience and family practice grew, family and social connection seemed to be a critical factor in creating resilience.

Family resilience captures the experience of resilience through the lens of familial relationships and interconnectedness (Patterson, 2002). Research then has begun to explore family resilience suggesting that, more than a characteristic, resilience is a process made possible by a set of qualities which can be strengthened or damaged (Walsh, 2003). The concept of resilience has shifted toward an understanding of resilience as a capacity that can be developed, fostered, and strengthened (Hartling, 2008; Walsh, 1998). It is understood in current research that resilience can be nurtured and that resilience exists not only within the individual, but also within the family unit. Family resilience is now viewed as “an ongoing, often emergent process in families” (Patterson, 2002, p. 237).

Family Resilience Theory

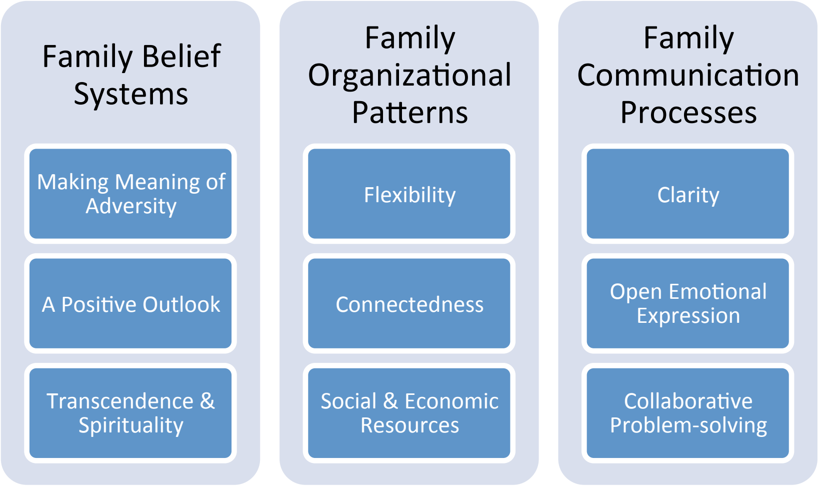
Two notable models have emerged to guide the study of and the practice in family resilience. Walsh's (1998) Family Resilience Framework and Patterson's (1988) Family Adjustment and Adaptation Response model (FAAR) are two of the leading theoretical frameworks designed with a resilience lens. Both of these models articulate the process of facing adversity and moving through it with increased resources. For the purposes of this study, due to its groundedness in social work practice, Walsh's family resilience framework was chosen as the guiding theory.

The family resilience framework, as developed by Walsh, is rooted in a systemic orientation. This framework identifies three key family processes—1) family belief systems, 2) family organizational patterns, and 3) family communication processes. Within each of these processes are three subconstructs, which are outlined below. Similar processes are identified in other resilience models. The FAAR model captures the interaction between four constructs: family demands, family capabilities, family meanings, and family adjustment or adaptation (Patterson, 2002). In a review of family resilience literature, Black and Lobo (2008) identified ten resilience factors that emerged: positive outlook; spirituality; family member accord; flexibility; family communication; financial management; family time; shared recreation; routines and rituals; and support network. The family resilience framework's processes and constructs offer a map that is congruent with research on theories of family resilience.

Walsh's conceptual map was developed to help families identify their strengths and vulnerabilities as they face difficulties, and grow their resilience. The processes and subconstructs in the family resilience framework can be used, not as a linear proscriptive approach, but as a guiding map for families and for practitioners. Through these processes families can experience resilience—facing risk, coping with its challenge, and emerging strengthened as a family unit.

In the following sections, each process mapped within the family resilience framework is identified, explored, and operationalized by its subconstructs. Both social science research and social work practice affirm the importance of these processes in positive family functioning.

Figure 1. Walsh's Family Resilience Framework



Family Belief Systems

Family belief systems are at the core of family resilience. Within these systems, the families create meaning, believe in their strengths, and connect to values and purpose beyond themselves. It is in these processes that families define themselves in connection with the world and with history. Beliefs emerge through the family's narrative and storytelling. Family belief systems encompass values, assumptions, biases, attitudes, and concerns of the family. Families facing crisis struggle to make sense of experiences that are atypical. Family units are strengthened when they are able to use belief systems to reconstruct meaning in life. Belief systems also include the process of seeking the good in a given situation, accepting what has happened, and hoping for best outcomes. These processes are rooted in the family's understanding of the world larger than themselves. Within the process of family belief systems, Walsh identifies three key protective factors that operationalize this process. These factors are: making meaning of adversity, a positive outlook, and transcendence and spirituality.

Family Organizational Patterns

Family organizational patterns are the structures upon which a family's resilience is able to grow. Families can use these patterns and structures to hold them afloat in the midst of trauma. Resilience is experienced when these patterns are able to bend and flex, rebounding, rather than breaking, from the impact of crisis. These patterns also include connections internally and externally. Resources available to the family are part of these organizational patterns as well. Connections and resources allow the family to organize their world and use this organization to rebuild after crisis has caused upheaval. The process of family organizational patterns, according to Walsh, includes these three factors: flexibility, connectedness, and social and economic resources.

Family Communication Processes

Families faced with adversity need communication processes in place in order to experience resilience. Communication processes that foster resilience allow for clarity and consistency, honor the sharing of emotions and empathy, and welcome collaboration and growth. These processes are the channels of functioning where families speak, listen, share, disagree, brainstorm, plan, joke, and decide. Within the concept of family communication processes, Walsh identifies three constructs that build resilience: clarity, open emotional expression, and collaborative problem-solving.

Each of these three processes, made up of the subconstructs, offer opportunities for families to experience resilience in the face of adversity. These processes do not operate independently of each other. Nor are they linear in nature. They are dynamic, intersecting, shifting, and overlapping as the family moves through crisis and resilience. For example, connection to a faith community has the potential to bolster both family belief systems as part of transcendence and family organizational patterns as connectedness. Family resilience framework serves as map for social work practice with families or with research.

Social Work Practice

Social workers have long been in the practice of building family resilience. The concept of resilience resonates well with social work practice, which, according to the International Federation of Social Workers (IFSW), is charged with enhancing the well-being of humans through social change, relationships, empowerment and liberation by intervention with people and their environment (2004). Resilience, as previously stated, emerged from the observation of people thriving despite existing in environments of risk and stress. Resilience compliments well social work's strength-based paradigm, the idea that in order to increase well-being social workers must illuminate the strengths which already exist. Additionally, the concept of resilience works well alongside social work's theoretical models as it considers the person-in-environment approach. Increasingly, social workers and other similar fields have been applying the concept of resilience to their practice (Greene, 2002). The concept of family resilience can be applied to all levels of practice settings from individual work to policy work though most current applied practice of resilience models is within individual and family therapy settings (Greene & Livingston, 2002; Tully, 2002; Walsh, 1998; Walsh, 2003).

Literature Review Summary

In conclusion, research makes clear that traumatic brain injury is a significant health concern. Of brain injuries, those designated as severe injuries carry considerable lifelong challenges. These challenges extend beyond the individual, impacting the family as a unit. Social work research and practice has paid little attention to STBI, leaving families without the support of social workers who are prepared to deal with the specific and complicated trauma that is STBI. Because it is a significant cause of death and disability and because it has been shown to cause considerable distress for the entire family, there is a need for social workers to gain an understanding of this experience.

Furthermore family resilience framework provides a useful lens through which to engage in social work research. TBI research has focused largely on stress and caregiver burden and has failed to capture the strengths-based perspective of social work practice available through the family resilience framework. Though social science research has increasingly turned to resilience as a lens for practice, research has not significantly applied this lens to the study of STBI. This study was designed to bridge this gap by exploring how families experience resilience as they moved through the trauma of STBI and to then ask what implications this might have for social workers in practice.

CHAPTER III

METHODS

This project was carefully constructed to explore the phenomenon of family resilience through STBI using a mixed methods exploratory research approach. This chapter reviews the mixed method research design, the instruments used, the participant selection process, the data collection, and the data analysis process.

Research Design

This study utilized a mixed methods design, with emphasis on qualitative data collection. Using a survey and semi-structured interviews, the project gained an expansive understanding of STBI experienced through the lens of family resilience. The quantitative elements gathered a breadth of information, established the presence of resilience within each family, and were used to support the qualitative research. The focus on qualitative design allowed for considerable depth in the research as the interviews gathered the complexity of each family's experience and the analysis reconstructed this lived experience from the data.

Additionally, this study incorporated elements of my own experience as part of a family wherein a member sustained an STBI. While certainly I could not entirely suspend my life experience, I made efforts to reserve my own bias and narrative while I completed the data collection and analysis. I did this by attending to my own internal processes, by allowing myself space from the project when needed, and by being clear with participants about my role during the interview process. After analysis, I compared my own family's experience and was able to then weave elements of my own family's narrative into the findings.

Permission for this study was submitted through the University of North Dakota Institutional Review Board and granted on February 21, 2012 and renewed on February 6, 2013 (IRB # 201202-277).

Participant Recruitment

Initially, I identified six families that might be included in this study (including my own). All families were known to me through connections resulting from my own family's experience with STBI. I knew none of the participants previous to my brother's injury.

The following criteria were chosen for participant selection:

- Diagnosis of severe TBI for a child in the family
- English as first language
- Known to me through my own family experience with STBI
- At least 6 months from injury

These six families were purposefully chosen as typical cases of families coping with STBI. Of the six families, five (my own and four others) completed both the survey and the interview. One family completed only the survey.

The families chosen for this study all had a child within the family sustain and survive an STBI. The injury of the child in each family was sustained between a year and eleven years previous to the time of invitation to the study. Given the nature of this study, purposeful convenience sampling determined the participants. The intensely personal nature of this study asked participants to share their traumatic journey with the researcher. Beginning with an established connection allowed participants to share openly, therefore it worked well to use my family's own network of connections to gather participants for this study.

Data Collection

Survey Design

Survey questions were developed through the literature and with guidance by a brain injury professional. The survey included four sections: 1) Family Information, 2) Information on TBI and your family member with TBI, 3) a support scale, and 4) the Family Resilience Assessment Scale. Each section was designed to be answered as a family unit. The instruments used were post-test only. The survey was available to families in hard copy or electronically.

The first two sections ("Family Information" and "Information on TBI and your family member with TBI") collected information on the family's experience of STBI that could easily be communicated in writing. Information gathered in these sections included length of time spent in medical settings, family make-up, and the cause of injury. These sections allowed for the interview to be limited to 90 minutes, lessening interviewer and interviewee fatigue and ensuring respect for participants' time. Additionally, collecting information ahead of time provided a framework of understanding for adapting interview questions.

The third section ("family support scale") was a 5-point Likert-type scale, which I designed to highlight the support experienced by the family pre-injury and at three points in time post-injury (first month, two to six months, and beyond six months). Informal and formal sources of support were identified with the assistance of a brain injury professional. Informal supports are those which families have around them organically, including extended family, neighbors, friends, and faith community. Formal supports are those that operate within a formal structure. These tend to be professional people or systems, such as doctors, counselors, and the local school system. Understanding that each family may experience support differently, space was allowed for writing in sources of support that may have been overlooked and for adding comments or explanation.

Lastly, the fourth section of the written survey was the Family Resilience Asssessment Scale (FRAS) designed by Meggen Tucker Sixbey. This assessment scale emerged from Tucker Sixbey's (2005) research project to develop a measurement tool by which to empirically validate Walsh's (1998, 2003) family resilience framework. In Tucker Sixbey's study, she created and tested a scale to measure family resilience framework by assessing the three constructs and the nine subconstructs developed by Walsh. The 66-item scale consisted of family resilience value statements that participants rated their family's level of perceived agreement or disagreement on a four-point scale. In Tucker Sixbey's study, the FRAS was administered to 418 participants (2005). After factor and reliability analysis, the FRAS consistently and reliably identified and measured six resilience constructs, rather than the nine suggested with Walsh's model, with an overall alpha reliability of 0.96. After reliability analysis determined a six-construct scale, Tucker Sixbey shortened the scale to 53 items. The 53-item FRAS was included in this research survey as a means to determine the family's measured level of resilience previous to completing the interview.

I developed the survey as one who has experienced moving through STBI. In addition, I sought assistance and feedback from a brain injury professional. Both experiences revealed a need for small adaptations within the questions, such as replacing a complicated inquiry about level of care needed with a more direct question and replacing a question about the loved one's coma with a question about the approximate length of time spent in a coma.

Interview Design

Interviews were designed to be semi-structured and open-ended. Semi-structured interviewing permitted freedom to adapt questions to the specific family, probe into the nuances of each family's experience, and engage in a more conversational interview. Open-ended questions allowed respondents to take their answers in organic directions and to answer with as much depth as they felt comfortable. An interview guide was created with grounding in Walsh's (1998) family resilience constructs and was further informed by my own knowledge of the experience being studied. The interview questions were focused on gathering information about the experience of STBI and about the family's experience of resilience in the midst of it. The guide was made available to families at the beginning of their participation so they could prepare for the interview ahead of time. Families also had time to discuss their responses together or with members of their family that would not be available to attend the interview.

While this project focused on the family as a unit, the interviews did not require any certain number of family members present. It was made clear to the participants that responses should reflect the experience of the family. Each family could then decide who from their family would participate in the interview. Four families elected to have two family members present. The fifth family had five family members present.

Interviews were conducted via Skype, a free web-based videophone service, or via phone, where Skype was not available. All interviews were digitally recorded in their entirety.

Data Collection Procedures

Upon approval by the University of North Dakota Institutional Review Board, families were first contacted by phone or email to discuss their interest in being a part of this research project. The methods and purpose of the study were discussed with each family. Following this conversation, families received the consent form, the written survey, and a copy of the interview guide. The contact letter, consent form, survey, and the interview guide can be found in Appendix A, B, C, and D respectively.

Participant involvement began with the consent form and written survey. All participants chose to receive the survey by mail. As a whole, the survey was designed to take no more than 30 minutes to complete.

Because this project involved the whole family, the consent form included information for adults as well as child-appropriate information. All members of the family were invited to participate. The purpose and protocol of the study was made clear and protection of family privacy was assured. Additionally, the consent form recognized the participants right to stop participation in the study at any time.

When the consent form and survey were completed, the FRAS was calculated and the family was contacted to schedule the interview. At the start of the interview, participants were reminded of the purpose of the study, the voluntary nature of their participation, and the protocol following the interview. Participants were recognized for honoring this project by their openness and were reminded of their right to pause or stop the interview at any time. Following the interview, families were welcomed to contact me with any additional responses, statements, or thoughts they had as they reflected on the interview and their family's experience of STBI. Upon completion of this study, participants were invited to obtain a copy of this project for themselves or for any professional whom they feel may benefit from this work.

Data Analysis

Quantitative Analysis

Survey responses from all sections were coded and entered into Excel. Quantitative data was analyzed using Excel and SPSS software. Frequency tables were produced for data from the support scale. For continuous data within the survey, the mean was calculated. The FRAS was scored for each family and the FRAS was measured for internal reliability. The FRAS was calculated previous to the interview in order to determine the presence of resilience within each family. After data analysis, the quantitative results were used to support the qualitative findings.

Qualitative Analysis

Interviews were digitally recorded and transcribed verbatim. The qualitative data that was analyzed included the data gathered in the interviews, and data from follow up emails from two families.

A four-step process based on the constant comparative method was employed for qualitative data analysis (Maykut & Morehouse, 1994). This method involves a process of exploring the meaning of the qualitative data and reconstructing the text to accurately capture the participants' lived experience. This method uses open-coding and constant analysis of data sets until categories are fully supported by the data. For this project, the steps were completed as follows.

Step One

The interview transcripts were printed and read in their entirety to gain familiarity with the data. During this reading, I noted emergent ideas and reoccurring words, phrases, and concepts on a discovery sheet, as a way of beginning to draw meaning from the data (Maykut & Morehouse, 1994). These words, phrases, and concepts provided possible data categories for future steps. The discovery sheet is included in Appendix E. As it was read, each page of text was labeled to identify whether text was interview or email response, the participant source, and the page number within that data set.

Step Two

To begin the open coding process, the interview text was read again. This time units of meaning were identified within the frame of the research questions. Units of meaning are smaller sections of the text that contain a stand-alone thought, concept, or idea related to the research questions (Maykut & Morehouse, 1994). These sections of text were coded by applying a word or phrase that named the meaning contained within. These units of meaning were labeled in the margin by a meaning code (a word or phrase) and the location code (where in the text it was originally located) and then cut into units of meaning data cards.

Step Three

Next, using a look/feel-alike guideline, the data cards were categorized within the frame of the two research questions. To categorize the data, a data card was examined to determine if looked/felt alike to any of the possible data categories on the discovery sheet. This would be the start of a category. Once the section of text was fit within a category, another data card was examined to see if, based on the look/feel-alike criteria, it also fit within the category. When a unit of text did not fit the existing categories, a new category was formed and all data cards already categorized were re-examined to see if the section would fit the new category. With every new data card placed in a category, the text already in that category were re-examined to make sure the data within the category still fit the look/feel alike criteria. This process continued until all the interview data were categorized. Categories were developed for 1) the experience of STBI and for 2) the experience of family resilience through STBI. These categories served as provisional categories (Maykut & Morehouse, 1994).

Step Four

To further develop and refine the categories, rules for inclusion were written for each provisional category. Rules of inclusion are propositional statements "that convey the meaning that is contained in the data cards gathered together under a category name" (Maykut & Morehouse, 1994, p.139). Rules of inclusion propose a statement based on the data. Following the writing of a rule of inclusion, units of text were compared again to ensure they fit within the rule. Units of text that no longer fit the rule of inclusion were removed and re-categorized. This process continued until categories emerged that were clearly different from each other, were fully supported by the data, and represented a recognizable reconstruction of the participants' experience. From this process, eight categories of the family experience of STBI and eleven categories of family resilience were identified. The codes from the data cards and their corresponding categories are listed in Appendices F and G. These categories are grounded in the text and, while each is related to the others in that they are each a part of the experience, each category stood on its own as a unique part of that lived experience.

Data Triangulation Mechanisms

To build reliability in this study, several additional steps were taken. Participants were invited to contact me after the interview via email or phone if responses or information emerged as they reflected further on the interview and on their experience. Two families sent further responses via email following their interview. Additionally, participants were invited to engage in data source triangulation by reviewing the qualitative analysis category results in a draft of Chapter IV of this thesis. Participants were invited to read the draft and provide any feedback on the categories or on the written draft. One family provided feedback via email. Furthermore the analyzed quantitative data were examined to determine how the data supports, or does not support, the qualitative findings. Lastly, Walsh's family resilience framework was compared to the categories of resilience that emerged from this study. These methods of triangulation added a level of completeness, fairness, and accuracy to the data collected (Patton, 2002).

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CHAPTER IV

FINDINGS

Sharing the journey of STBI is a vulnerable experience that required these participants to revisit uncomfortable, unflattering, and painful spaces. This chapter explores the journeys and experiences of the families who were gracious enough to share their story for this project. The stories and experiences of these families are studied and discussed with the hope that their journey will be an opportunity to shed light on family resilience and STBI. In this chapter, the results of the study are described starting with the survey results and then the interview results. Interview results are explored through identification of the emergent categories with multiple samples of dialogue that capture each category.

Six families took part in the study survey and five families completed both the survey and the interview. For the purposes of clarity in results, only data from the five families who participated in both the survey and the interview will be considered in the findings.

Survey Results

Of the five individuals with an STBI whose families were interviewed, all were injured a motor vehicle accident. None of the families were present at the time of the injury; all families learned of the accident by a telephone call. The most recently injured was two years post-injury at the time of interview. The others were injured between two and a half, and eleven years previous to the interview. One family includes only the child with an STBI. The other families have between three and eight children in the family, including the child with an STBI.

Of the five families that completed the survey and interview, the reported length of time the injured family member spent in a coma ranged from 35 days to 3 months with one family indicating their child still remained in a "state of minimal awareness." Time spent in the hospital post-injury (including ICU, "step-down" units and inpatient rehabilitation) ranged from four months to seven months. Two families lived within an hour drive of these care facilities. For three families, these care facilities were located between 160 and 500 miles away from home. In the participant sample, all the individuals with STBI currently live in their family home. All the participants with STBI currently require high levels of care for daily living activities—three require 22-24 hours of caregiving per day, two require between 6-16 hours of caregiving per day, depending on mobility needs.

Results from the Family Resilience Assessment Survey (FRAS) show high levels of resiliency in all participating families. The FRAS scoring has a spread from 60 to 240 with higher scores indicating higher levels of resilience. The mean scale score for FRAS is 157.48. The spread of scores from the five participating families was 145-187. The mean score for participating families in this study was 163. The FRAS results showed high internal consistency with a Cronbach's Alpha of 0.94 for the 53-item scale.

The same five families completed a support scale to identify where families felt support throughout their journey with STBI. The scale indicated high levels of support from both informal and formal supports for all families during the first month after injury. Formal supports (including doctors, social workers, therapists, nursing staff, CaringBridge, home health care, brain injury associations, and counselors) showed fluctuation as time passed with some supports diminishing or becoming less helpful and new supports stepping in, such as rehabilitation. Overall informal supports (including extended family, faith community, neighbors, friends, and civic community) showed a diminishing trend as time passed. Within formal supports in the first six months after injury, nursing staff was ranked as highly supportive among all families and Caringbridge was ranked highly supportive by all families who had access to this support.

Interview Results

Through the use of the constant comparative method the qualitative data categories were identified as outcomes that addressed the research questions. Because of the nature of the design of the interview questions, categories materialized around both—1) How have families experienced the journey of STBI and 2) What has resilience looked like for these families? These results are presented and explored in depth in this section using examples of data for each.

Categories of The Family Experience of STBI

Eight categories of the family experience of STBI emerged from the interview data. They are: A Long Road; Rollercoaster of Emotions; Exhaustion; Complicated Grief; Navigating Complex Medical Systems; Unknowns; Isolation; and The Loss and The Rebuilding of Normal. These categories are grounded in the interview data and all are linked, with each affecting and interacting with the others.

Figure 2. Categories of the Family Experience of STBI

A Long Road Explanation: *The affects of STBI continue for a lifetime. The long-term nature of STBI makes all the other categories all the more challenging.*	Rollercoaster of Emotions Explanation: *Recovery feels like two steps forward, three steps back. With each step of progress, there is joy for healing and sadness for what should have been.*
Exhaustion Explanation: *Recovery requires so much energy, sacrifice, finances, and commitment; we feel depleted.*	Complicated Grief Explanation: *We grieve the child we once knew, yet are grateful our child survived*
. Navigating Complex Medical Systems Explanation: *We were forced into a new world of medical settings. We felt confused with, frustrated by, and grateful for medical teams. We had to depend on this world and learn to question it.*	Unknowns Explanation: *We were in the dark about what was ahead; even when it was explained to us, we didn't know what was ahead.*
Isolation Explanation: *No one knows what to say to us. Support diminishes. We find ourselves no longer able to connect like we used to.*	The Loss and The Rebuilding of Normal Explanation: *The complex process of both grieving the loss of what was expected and what previously had been and choosing to actively re-create family norms*

A Long Road

To understand the family experience of STBI, it must first be clear that the experience of dealing with STBI is long-term. This category emerged from every participating family repeatedly. It is perhaps this part of the experience that makes STBI such a unique type of trauma. The experience of STBI includes facing the shock of injury, sitting in the ICU waiting room, and unrelenting grief, and all these elements of facing STBI are complicated by the permanence of this experience. Healing after STBI is about long-term care and recovery. The longevity of STBI is part of every other category that emerged during the interviews. Every component of the experience of STBI is experienced long-term. It is, as one mother put it, “a 24-hour, 7 days a week, 52 weeks a year job. All the burden falls on me.” STBI for families is an experience of long-term care and recovery.

In one interview, I used past tense to describe coping with STBI and the participant quickly reminded me that coping with STBI is never past tense. They as a family, she suggested, didn’t “get through it,” but are instead, over two years post-injury, “still in the process of getting through it.” Families with STBI are still coping with it, even years after the initial injury.

Families will begin to understand slowly that healing from STBI is a long path. “I had no way to have any clue to the road we were on. I’m thinking that some of the nurses would make references to- ‘this is a long road,’ but at that point a long road to me meant maybe two weeks,” stated one mother describing those first weeks after the injury while their family waited anxiously for her son to regain consciousness.

A couple weeks after the injury, one family was told their injured daughter would never recover. To which a friend of the injured daughter declared that he was never giving up on her. The mother describes making what turned out to be a long-term choice at that time, “At that point, I decided I was never giving up either. And here I am, eleven years later and still not giving up on her!”

“As time goes on, it gets so much easier, but yet so much harder. In the beginning few years, you are still optimistic that you are going to have a breakthrough. As time goes on, year after year after year, you realize that the only way you are going to have a breakthrough is through a miracle," said one mother discussing the challenge of on-going care and recovery.

Throughout the remaining categories, the experience of this trauma being long-term will repeat itself, as the long-term nature of STBI permeates every aspect.

Rollercoaster of Emotions

From the moment of injury to long-term rehabilitation, families dealing with an STBI experience a rollercoaster of emotions. Families describe hearing of the accident, experiencing shock, and being suddenly and traumatically thrown into a new reality. In the immediate aftermath of the injury, there is fear, hope, despair, and shock all mingling in the same moments. Doctors and nurses offer good news, bad news, confusing news, and news that could be good, bad, and confusing all within the same breath.

"I remember that every time the neurologist would walk into the [hospital] room, I would feel like there was both fire and ice in my veins. I was terrified," described one mother.

Of those first days and weeks in the ICU, a parent stated simply, "It was chaos." Another said, "It was so surreal. I couldn't even wrap my head around that it could be life changing."

"You just pick yourself up off the ground and, all the sudden, you would just get hit in the gut again with another doctor saying something… I can remember family meetings they would have in [the hospital] where the whole family would be just absolutely falling apart and angry at the whole world because we weren't hearing what you want to hear," explained one parent about the ups and downs of their experience after STBI.

“I remember the roller coaster of emotions-- one day being optimistic, the next day the rug being pulled out from under us,” shared another parent.

Four months post-injury, one patient was moved to a different hospital to undergo a surgery, for which over several frustrating weeks his parents had been advocating. Following the surgery, the son with an STBI had an excessively high and erratic heart rate, which the medical staff could not seem to explain nor regulate. The mother describes the continued rollercoaster during this frustrating time as she sat awake in a strange, new hospital. “I couldn’t sleep. I’m sitting there staring out the window. It’s snowing like crazy… They’re calling in cardiologists and epidemiologists and all these-- I don’t know. It was just so surreal sitting there just not knowing, and feeling so let down because I thought we were making progress… and yet no one seemed to know what was going on with [my son].”

Exhaustion

Dealing with STBI in the family is exhausting—emotionally, physically, and financially. As previously stated, dealing with STBI is a rollercoaster, and this rollercoaster lasts into the future, as the path to recovery is slow. The result of this is an exhausting experience for families.

Physically, families reported facing exhaustion. In the days spent in hospitals, families shared stories of staying up all night for nights in a row, of sleeping in the waiting room every night for months, of not returning home for weeks, months, or, as was the case with one family, two years. Describing an emotional and physical crash after two months in the hospital, one mother explained, “Everything in me was depleted. I couldn’t eat. I couldn’t sleep.”

As weeks turn into years, families learn to manage, to develop new routines, yet still report physical exhaustion. “I remember saying to [my husband] one time that I had nothing left at all. I had nothing for me much less for him.”

As a father spoke about the long road of recovery, he articulated the family’s dedication to healing, yet at the same time said, “Some days are brutal. You just like—I can’t do this… Sometimes things get so overwhelming that really the only option you have is to do the next best thing, just to do the next thing… just one more time.”

Financially, families face long absences from work, long distances to care, and the cost of creating a new life for long-term recovery. These costs include renovating homes to accommodate the injured child’s needs as well as the cost of equipment needed for daily living, such as adaptive equipment for therapy activities and vehicle adaptation for transportation.

When standard therapy modalities did not seem to be working or were in need of a boost, all the families participating in this study explored alternative therapies. In choosing an alternative method for therapy, one family said, “It meant that our insurance wouldn’t pay for it and it required twice as much from us as a family.”

Emotionally, the exhaustion felt by families is clear. From the shock and pain of the initial injury to the rebuilding of “normal,” families express intense emotional exhaustion. One family described how the disability from STBI has effected their child’s memory and functioning, “She can’t remember that we’ve told her 716 times that you’re washing your face with soap at night, but she has to keep asking. She has an added dependency… and that just kind of wears on you. That’s where at the end of the day, you find yourself emotionally unable to continue coping." This exhaustion requires, as the family went on to discuss, finding new resolve on a daily basis.

One mom expressed the challenge of keeping up with the emotional demands of long-term caregiving and the real truth that, regardless of whatever else is going on, with the care of a child with STBI, "you are never really totally gone."

Complicated Grief

Dealing with STBI involves a complicated experience of grief. Families are grieving the injury, yet often the prognosis is entirely unclear leaving families unsure of even how to grieve. As families move into long-term care, they continue to grieve the loss of the child they once knew while also clinging to and fighting for the continued hope of recovery. The experience of STBI is slow, even in the way families begin to understand the injury itself. As families understand the injury and the long-term recovery, the sense of loss changes. Families do the work of recovery, yet are overwhelmed at times with grief when recovery is slower than expected or when the exhaustion of cares seems to be too much. Said one father, "It's this really weird mix of grief and awareness and loss and yet almost feeling like you shouldn't be doing that because then you take away your hope for recovery. It's a difficult complex mix of those two emotions."

Responses from families indicate the complicated nature of this grief. "I was very aware that every time I entered that [hospital] door, I just wanted to fall onto the floor and just refuse to participate in this nightmare," shared one parent about the weeks and months while their son was in the hospital. Similarly, another mom talked about her grief while her daughter was in the ICU, "I wouldn't leave the hospital during those first few weeks. Part of it was not wanting to leave; the other part was I couldn't stand the sight of a mother and daughter together, or a young couple laughing and holding hands. It was just too painful… I remember having to keep myself in the 'right now' because thinking about the past was too painful and the future was too scary." Many years after the injury, this grief remains. As one parent said, "I am happy, but I don't remember what it feels like to not have that broken, achy, painful feeling. It… is my new normal. I am happy with the way my life is going… but nothing can take away the sadness of what was lost."

Within this grief there also exists a sense of anger and unfairness. While anger was not a first response from participants, it emerged during the interviews as a complicating part of their grieving process. "Some days we need a triple supply of grace to deal with hurtful memories, to deal with the anger and unfairness of it all, to deal with people who mean well, but they're still hurtful." Another family said, through tears, "Sometimes I just get so mad at what this accident has done… It's changed her so much and made her so unable to walk or move." One mother said simply, "You just wonder, why us?"

The grief gets further complicated as time goes by and families must grieve the loss of expected development. Families describe watching peers to their child with an STBI move through typical life stages. One mother said, "I won't ever get what I thought I was going to have."

Navigating Complex Medical Systems

Families going through STBI are forced into a new and foreign world of medical settings. Families must depend on this world while, at the same time, families must learn to question it. Weaved into each family's story were almost contradictory narratives wherein medical professionals and medical settings caused confusion, frustration, and deep gratefulness. Families learned to be both appreciative and critical of medical staff and medical settings.

One family described getting lost in a hospital looking for their son with an STBI who had just come out of surgery. They describe being lost in the hospital, getting wrong instructions from staff, feeling confused and ignored, knowing where they needed to go, but not being able to find the right route. The parents expressed, “It was indicative of the whole journey. Nobody knew where they were going. We were sitting there wondering if everybody had forgotten us.”

Families shared stories of confusion and frustration over and over. “I didn’t really understand all the terms and stuff and exactly what was happening,” said one sibling. “I felt like I never understood what his injuries were for so long,” a parent shared. “We always had trouble catching the doctor… And we didn’t know what to ask.”

One mother discussed how, even when they were able to catch the doctor, she often didn’t know how to comprehend what the doctor said. “I had no understanding of this brain injury and I don’t think I could have processed it. All I did was hold on when the neurosurgeon or neurologist would say, ‘Well, the CT Scan doesn’t show any new bleeding.’ Well, then, I would grab onto that. I don’t even know what that means. I don’t even know what does it mean if it’s bleeding…. Well, it seemed like a good thing, so you hold onto that.”

Two families noted, in particular, stories of entirely contradictory medical direction from a hospital setting to the inpatient rehabilitation setting. One family was told their child’s tracheostomy tube could not be removed and within a short time, they were moved to a new setting where plans were immediately put into place to remove the tracheostomy tube. A second family shared a similar story regarding treatment of spasticity.

Families shared about the confusion of getting contradictory medical advice. One mother described how some experts said that stimulation is key to regaining consciousness while other experts said rest and calm is the key. “And even the doctors don’t know. There is nobody that can tell you exactly what’s the right thing to do.” While certainly all of these families expressed gratefulness for the care their children received, the confusing, sometimes contradictory, medical direction in the midst of grief and trauma, left families feeling vulnerable and unsure of whom they should trust.

As families begin to learn more about their child’s medical condition and about how to advocate for best care, they, at times, find themselves frustrated with the medical field. Families begin to advocate as they realize that best medical care is, to some degree, dependent on the advocacy of loved ones. Families must learn how to listen for what is important and how to ask questions. With many nurses, doctors, therapists, and hospital staff, these questions and advocacy are welcomed. Yet families had to also deal with less helpful responses, such as when family involvement is seen as intrusive or when facilities are not open to new approaches. Learning the skills of medical advocacy was identified as part of the journey. “I realize now [many years later] that a doctor isn’t God. He can make mistakes, he can be wrong, and I need to question. I do question. If something doesn’t feel right, I question.”

One family described how just the process of trying to decipher how to connect with the right people in the inpatient rehabilitation hospital in order to communicate was exasperating. “It just felt like… you couldn’t get your hands on the person or people who could really make a difference or do what needed to be done. Always the chain of command was maddening.”

Families also shared about feeling as though medical staff dismissed progress. One mother described when her injured son opened an eye for the first time after weeks of being in a coma. “All the doctors and nurses poo-pooed it right away, ‘He didn’t [open his eye]. It was just a reflex. Just something that happened.’ We knew for sure… [he] did… [he] opened his eye.”

Dealing with the medical field was not all bad. Families were overall exceedingly grateful for the care their loved one received. Families described prompt medical attention as life-saving for their injured child. Nurses and therapists tried new approaches, communicated empathy and hope, and were champions for the healing and care of their injured children.

Families also shared stories of getting clear and careful information from medical staff. When given complete information with clarity, families felt included in their child’s care and felt assured that their child was getting good care. Families appreciated reassurance that medical staff was doing the best they could to bring their children to the best recovery possible. Doctors, nurses, nurse aides, hospital staff, and therapists demonstrated high levels of compassionate care.

In the midst of grief and exhaustion, families dealing with STBI must also learn to navigate multiple complex medical systems. This process, at times, leaves families confused and frustrated and, at other times, leaves families feeling exceedingly grateful. Because families will continue to be involved in medical settings—from out patient rehabilitation to home health care—for the long-term, this sense of both frustration and appreciation is a lifelong tension.

Unknowns

Families experiencing STBI face a long road of unknowns. From understanding STBI itself to grasping for prognosis to observing other individuals with STBI recover very differently, families must deal with a high level of ambiguities and unknowns.

As was discussed previously, medical professionals offer information, yet they, too, face many unknowns with STBI and, since every brain is effected uniquely, even the known prognoses are not always clear. One father discussed being told that brain bleeding and brain swelling will likely happen in the first three to five days. "I think I knew pretty early that is was really, really serious. But then when he didn't have brain bleeding and… when he didn't have brain pressure within the first three or five days, I thought, well, we got past that." He went on to explain that this sense of having gotten past that was short-lived as his injured son's brain pressure spiked dangerously high for several days after he was past the expected critical window. In talking with the family about it, doctors could only guess why this was happening. It was, in this family's experience, a horrible time of waiting and being surrounded by unknowns.

Families described over and over the anxiety of simply not knowing. "We just didn't have a clue what [he] was going to be like when he started to wake up. That was pretty scary." "One of the things looking back now, I am very aware that we had no idea what a traumatic brain injury was. We had never known anyone who'd been through this. We didn't even know what implications that had for [her] recovery. We were just totally in the dark about what it meant for her life ahead."

The process of regaining consciousness after being comatose is in itself mysterious. Families want to know when their loved one will "wake up," yet for most with an STBI the waking up is a process, one that can take many shapes. "It took a couple of months… it was just like the slowest kind of waking up. It's nothing like a movie. Someone doesn't just… be in a coma for 30 days and then just wake up and…are able to start eating and drinking and everything. I think we had that fantasy in our heads for the first couple of weeks… but then we knew the longer he was in a coma, the more brain damage he probably had."

These unknowns, as with the other elements of STBI, last into the long-term. Even as families left the ICU for rehabilitation, the prognosis remained unclear. "[She] was in ICU for a month and then they moved her out. That was a scary time. She was still asleep and I didn't know how they were going to start rehab when she was still in a coma."

Throughout recovery, unknowns persist. Why some functioning recovers quickly while other functions may never recover is unknown. Each child in this study is experiencing recovery in very different ways, despite having had similar injuries. "She's been experiencing incredible things [in her recovery] and… there's just this whole agonizing over the levels at which a brain injured person recovers and how [her] roommate had an accident as well and wasn't recovering like [our daughter] was. It's just brutal. You're excited for the recovery that you see and you hope for more and more. Then you see others, other families, and other patients that want the same thing and don't get it. Then there's others that are recovering even faster than you, " said one father.

Isolation

Another emergent category within the stories of families experiencing STBI was a sense of isolation. Families describe this isolation as having ebbs and flows. While families describe high levels of care and concern by their communities, there still seems to exist a pervasive sense of isolation, a sense that others cannot understand or know this grief of loss that combines itself with a sense of hope for recovery. Said one mother, "There's not a lot of people that you can sit and visit with that really get it." The emotions are deep, intense, and unrelenting. One father said, "I know that I personally have gone through some pretty significant times of isolation and feeling as lonely as a person can feel. I'm in a community where people care. I know they care and yet it seems so distant. They just don't know [what to say or how to help]. Nor do I know how to ask for their help or communicate what I need."

Repeatedly, families said that, although people in the community care, most people do not know what to say and many, therefore, choose not to say anything. "People walk away. They don't know what to say." "I think in some ways because some people in the community had a hard time understanding what we were going through as a family... with some people the relationships aren't as strong as they were before because, like, I heard several people say something to the effect that they didn't know what to say or do when they're around us. We have this really close community and then this thing happens to our family and there's this area where we can't relate anymore."

One mother shared about the frustration of others not acknowledging her son now that he has an STBI and, with it, lingering disabilities. She described how people would act as though he was not present, asking her how he was doing rather than talking to him directly. “I wish that everyone in the world could just be given the ability to know how to communicate with somebody that isn’t just like them.”

Because families, to some degree, put life on hold in the weeks and months following the accident and then must re-establish a new normal, this brings with it a sense of being out of sync with others whose lives have continued to move forward.

Over time, the overwhelming support displayed at the time of injury tends, perhaps naturally, to wane. Families feel, as one mother put it, “Everybody that was there at the beginning slowly, slowly, slowly go on with their lives and you’re still living it.” Another father said their family has watched the peers of his injured daughter disappear. He says, “It represents a lot of hurt and woundedness. And it’s perceived by us sometimes… that people have abandoned us… [even though] I know that’s not what they intend.”

Isolation emerges as families describe feeling disconnected from their community and the people around them. Families see this as happening partly because those around them no longer know how to relate to them and partly because the family has been forced into a new reality, which has changed them. At times, families seem to think the isolation is merely in their perception and, at other times, the isolation seems to be overwhelming, and obvious.

The Loss and The Rebuilding of Normal

Dealing with STBI changes families. It impacts their dreams, their development, their routines, their recreation, their connections, their faith, and their interactions with the world around them. After STBI, families sense a loss of normal and then slowly begin to rebuild what will be a new normal.

Families expressed how STBI changed how they relate to each other. For a long time, the family naturally focuses on the injured child. Siblings and parents experience role confusion, having to adjust themselves and figure out how they fit into these new family relationships where recovery and healing are now the singular focus of family energy. One mother used the word, “tumultuous” to describe how STBI affected the balance in the family. As time passes, the family relationships will shift again, as they must, to make room for incorporating the injury into more balanced family roles, where family members can share opportunities to be the focus of energy.

Families shared about the loss of normal routines. Parents left their jobs. Siblings missed school. Extended family stepped in to help with parenting. When trauma and rehabilitation hospitals were hours away from home, families lived in hotels, with family, or in hospital housing. And these changes in what was regular life lasted for months or years. One mother describes leaving her home when she got the call about the accident. “I walked out the door that Sunday morning… and I didn’t come home for two years. I never set foot in my house again for two years.”

Again, as time passes, these changes in routine must adjust. Injured family members eventually came home. For all these families, coming home meant gaining some semblance of normal back, yet coming home also meant managing appointments for therapy, doctor visits, and home health care. Scheduling and communicating with all the healthcare services, social services, special education, and therapy services is very time-consuming. One mom figured she spent 25-50% of her time just scheduling, contacting, and planning on a weekly basis.

Parents shared about feeling a loss of plans. With a child with STBI, growing older no longer contained the freedom it once had. While their friends are beginning to experience the freedom that comes with children becoming independent adults, parents of a child with STBI face a future that may not contain such freedom. One mom said, “I confess jealousy [of parents whose kids are grown] because life is different for us.”

The loss of normal is dynamic and changes with the family’s life stages. Regardless of its particular shape, what is clear is that for families with STBI family norms will never again look the same.

Summary

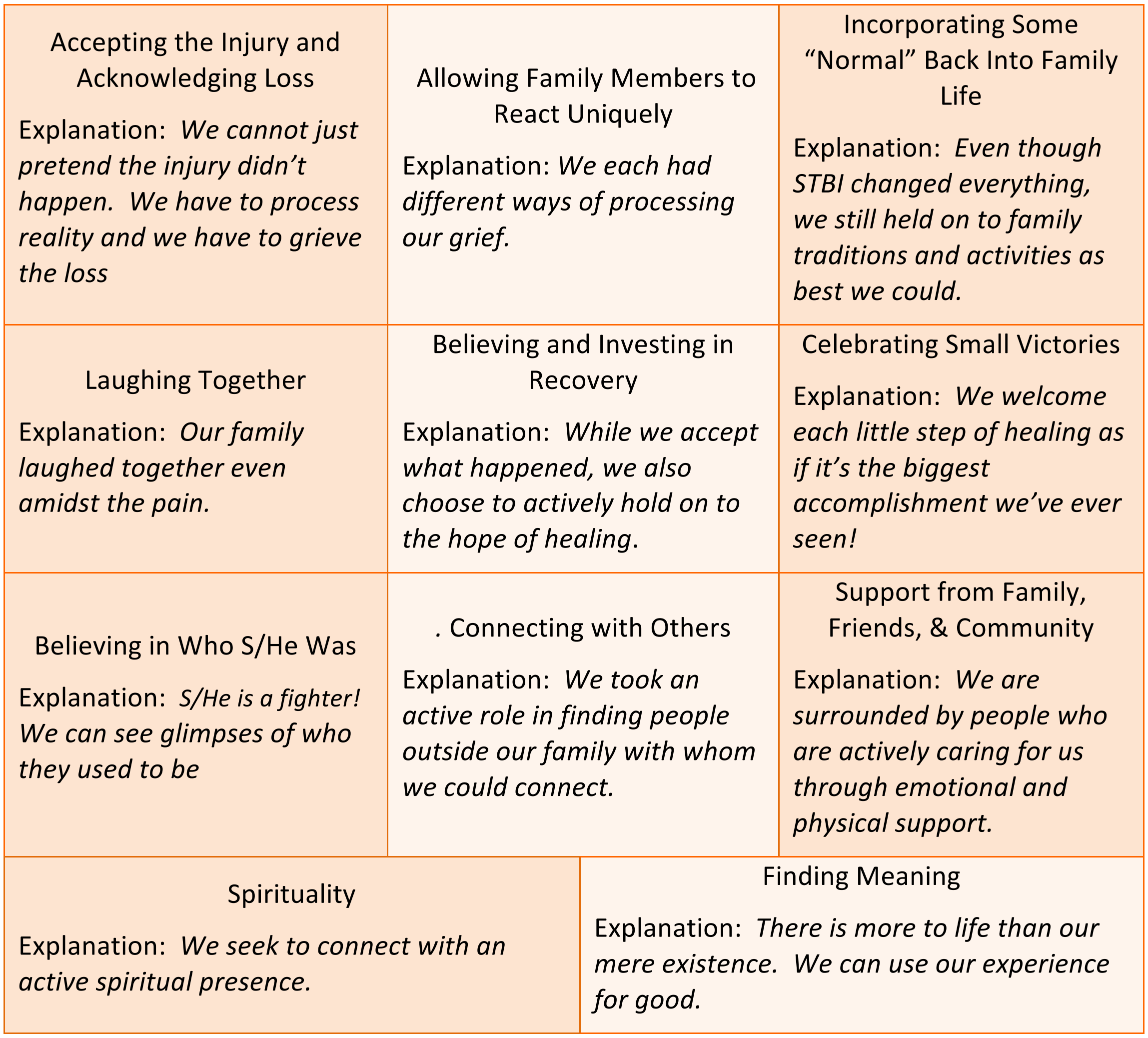
The family experience of STBI is life changing. Families expressed their experience within these eight categories. All these categories interact and affect the others as families move through the stages of recovery and healing. Families experience STBI as: a long road and a rollercoaster of emotions wherein isolation, exhaustion, grief intermingle, and wherein navigating the medical system and wrestling with unknowns are constant demands.

Categories of Family Resilience Within The Experience of STBI

The families invited into this project each demonstrated high levels of resilience, according to the FRAS scale score. They learned lessons and they found paths to get through all the pain, confusion, and exhaustion. Where in this journey were families able to experience resilience? The categories that emerged from the interview data shed light on how these families experienced the resilience captured by the FRAS.

As families discussed how they are able to move through the trauma and challenges of dealing with STBI, eleven resilience categories emerged. These categories were: Accepting Reality and Acknowledging Loss; Allowing Family Members to React Uniquely; Incorporating Some "Normal" Back Into Family Life; Laughing Together; Believing and Investing in Recovery; Celebrating Small Victories; Believing in Who S/He Was; Connecting with Others; Support from Extended Family, Friends, and Community; Spirituality; and Finding Meaning.

Figure 3. Categories of Family Resilience Through STBI



Accepting the Injury and Acknowledging Loss Explanation: *We cannot just pretend the injury didn't happen. We have to process reality and we have to grieve the loss*	Allowing Family Members to React Uniquely Explanation: *We each had different ways of processing our grief.*	Incorporating Some "Normal" Back Into Family Life Explanation: *Even though STBI changed everything, we still held on to family traditions and activities as best we could.*
Laughing Together Explanation: *Our family laughed together even amidst the pain.*	Believing and Investing in Recovery Explanation: *While we accept what happened, we also choose to actively hold on to the hope of healing*.	Celebrating Small Victories Explanation: *We welcome each little step of healing as if it's the biggest accomplishment we've ever seen!*
Believing in Who S/He Was Explanation: *S/He is a fighter! We can see glimpses of who they used to be*	. Connecting with Others Explanation: *We took an active role in finding people outside our family with whom we could connect.*	Support from Family, Friends, & Community Explanation: *We are surrounded by people who are actively caring for us through emotional and physical support.*
Spirituality Explanation: *We seek to connect with an active spiritual presence.*	Finding Meaning Explanation: *There is more to life than our mere existence. We can use our experience for good.*	

Accepting the Injury and Acknowledging the Loss

Resilient families are able to both accept the reality of the injury and acknowledge the grief of loss. There is inherent tension between these two concepts. Families wrestle with the grief of loss, while also accepting the reality of a traumatic shift in their family's life. Accepting and grieving seem to emerge linked, even as these concepts seem to be in dissonance. Families recognize the loss in the family, yet know they cannot dwell in that space. Accepting the injury and acknowledging the loss together allow families to move forward. This means families learned to cry together, to experience the pain, as well as to face the day and the work of recovery at hand. As one mother put it, "It sounds strange, but I must embrace what happened. It is what it is. Don't pretend it didn't happen because if you pretend it didn't happen and you don't talk about it—it destroys you."

Families expressed accepting and grieving in terms of focusing on what is here and now. "You can't live past today. You live in today and don't even think about tomorrow because it's too much." Another family voiced, "We just kind of, we just go to do the next thing. We just keep moving forward. We know we can't look back."

"[The child with an STBI] says almost everyday, 'I just wish I was better I want to be better right now.' You know, she doesn't want to go through the therapy every day; it's too hard. All of us would want the hard things in our lives to just go away and we would want healing to come faster than it ever does." In these words, one family expressed that dealing with STBI is hard and healing is slow, yet they also spoke with the conviction that they must keep moving forward, even with aching hearts.

When interviewed, these families shared honestly about having to accept the injury and also feeling the pain that comes with it. "Because it is what it is. And we'll continue to pray that maybe someday something will change because miracles do happen, but in the meantime, we just keep going."

Allowing Family Members to React Uniquely

Families struggling through the trauma of STBI are more able to experience resilience when, as a family unit, they allow family members to react uniquely. Family members will inevitably all be experiencing the trauma of STBI in their own way. Being at different stages of development, having had each their own relationship with the injured family member and with each other, and each understanding the world through their own perspective means that family members will certainly experience STBI distinctively. Families exhibited resilience through STBI by seeing these unique experiences and allowing family members the grace to respond, and react in their own way. For none of the participants was this process an easy task. In fact, no participating families even specifically recognized their own family doing this. However, an idea that emerged from their stories was one of families finding resilience, even as their own individual reactions clashed.

For one family, these individual reactions meant a separation within the family three years after the injury. Yet even amidst the pain of family separation, the participant articulated that individuals deal with the trauma of STBI differently. The ability of the family to move through this pain with resilience perhaps matters more than forcing nearness where distance is needed.

Siblings of the injured family member often cannot understand what is happening. One mom explained the challenge of having her injured son's siblings at the hospital. The family had to learn to adjust visitations in a way that supported recovery, and also allowed the younger children to understand and process the trauma in their own unique way. “We would bring [my younger children] to the hospital so they could visit. It was really hard because the whole time [the siblings] were there, [they would ask], ‘When is he going to wake up? When is he going to wake up?’ And I just always had to say, ‘He’s going to wake up and I can’t say for sure when. It might be next week and it might be the week after or longer….’ I just never had answers and they’re very young and that was really hard for them to not have answers. It just caused their anxiety to go through the roof, too.”

As families move out of the ICU and into long-term recovery, families face the challenge of allowing family members to continue to grow and develop. One brother spoke about how hard it was to move forward with his own life pursuing studies at a university a distance from his home where his family and sibling who has an STBI live. “Now I’m away. I’ve come home many of the weekends, but… there’s part of me that feels like I’m coming home too much because it’s distracting from work and schoolwork…. Yet I almost feel bad if I’m not home being with [my sister] and my family.”

One family discussed recognizing that a family member needed the support of mental health services in order to get through the trauma. While this was not part of their family norms previously, they recognized the need in their family member. They were able to support their family member to seek out services and medication in the way that she uniquely needed it at that time.

Long hospital stays for injured family members mean exhausting days for families. One family shared about a time when a family member was feeling entirely burned out. During that time, she described not even being able to go down to the hospital. “I couldn’t see [my injured daughter].” She could no longer carry the heavy pain of spending long days beside her broken child and just needed to be allowed to rest. While it was undeniably a very rough time for the family, they were able to respond to her need for rest and respected her need to have her own reaction.

Families with children also described how some were able to put their lives on hold and be physically present as part of their sibling’s recovery while other children either needed to hold on to the routines of their pre-accident life or did not have the flexibility to put life on hold. One family described how some siblings were present all the way through while other siblings ignored and stayed away.

In my own family, I put my studies on hold to be physically present in my brother’s recovery. Yet I had siblings for whom this would have been an unhealthy choice. For some siblings, their own reaction and life circumstances demanded a different response. Navigating these unique responses was an underlying idea that developed in interviews and was clearly both painful and challenging for families. Furthermore, no families in the study claimed to have responded perfectly to the challenge of allowing family members to respond distinctively. Yet it is clear from their experiences that their ability to move through this time with resilience was due in part to their honest wrestling with the challenges of moving through trauma as a family when each family member has their own unique response.

Incorporating Some “Normal” Back Into Family Life

Families experienced resilience through STBI by incorporating elements of their pre-accident life into life after STBI. As articulated earlier, STBI causes tremendous disruption for all facets of family life. It disturbs accepted family roles, changes expectations, increases stress, puts activities and involvements on hold, and altars plans at every level. Despite this, families identified an ability to preserve some family norms.

One mom identified that a source of resilience for her family was preserving order through maintaining organization and scheduling. STBI, in a sense, takes over the entire family life. In order to preserve themselves as a family, she described focusing her energies and taking pride in finding ways to meet the needs of all family members including making the many appointments for therapy and recovery for her son with an STBI. Having always been an organized person, she held onto this sense of normal and used it to help their family move through this challenging time.

Another way families expressed an ability to preserve pre-injury norms was by saying, "we just did what we had to do." This sentiment came through when families were asked about how they were able to cope. They relied on norms they had established pre-injury. For my family this meant we played games, which was a family tradition, while sitting long hours in the waiting rooms. For another family, this meant preserving a sense of individuality and allowing their children to maintain their own activities even as the family became tied up in the demands of recovery and rehab activities. For yet another family, this meant decorating the house for Christmas as usual despite the fact that nothing about Christmas felt usual. This family shared, "We had Christmas in the [hospital] room. We tried to maintain at least a little bit of family traditions of the holiday, and try to find some kind of gratitude or thanksgiving—at least that she's alive and that we can be together as a family and that God's been helping us as we walk through this situation." In their own ways, families experienced resilience by being able to hold onto particular parts of their identity, as individuals and as a family unit.

For families this also meant allowing the family to continue to develop and grow. This can be particularly painful as life moves forward, yet families experiencing resilience find ways to allow growth and development. One family described how previous to the injury, the family was very active and travelled a lot. Since the injury, these trips were no longer possible. However, after several years of rehabilitation, the family was newly ready to re-introduce these adventures and went camping again for the first time four years after the injury.

Laughing Together

It, at first, may seem inconsistent to discuss humor in the midst of grief, yet participants both discussed and demonstrated the use of humor as part of their experience of family resilience. Families demonstrated an ability to find humor in the pain, to discover laughter among the hurt, and to allow lightness to emerge even in the darkness of loss.

When asked about what coping looked like for their family during the first weeks after injury, the family member with an STBI jumped in energetically to say, "They looked awesome." To which, his mother joked back referring to the weeks during which her son was in a coma, "Well, for you! You slept through it all!"

In my own family, as we spent many hours waiting, we found comfort in laughter together. When my brother was running a fever while he was in a coma, we suggested perhaps it was the Bieber Fever. Our laughter often turned into tears as the familiarity of laughing together would remind us of what we had lost, as we mourned that my brother wasn't able to offer a quick retort to our suggestion that he had the Bieber Fever. Laughing together offered a rest from the grief, offered the comfort of normal even for a moment, and drew us as a family closer together.

Another family identified humor as an indicator of healing as a family. Even though everything has changed for their family, even though rebuilding relationships with each other and with the injured sibling has many challenges, the parents recognized healing in laughter. They said, "the siblings make an effort to recognize (their sibling with an STBI). They engage her in conversation. They have a lot of fun with her because she's got a great sense of humor. My son said, 'When I'm around [her], I think I should go into stand-up comedy because everything I say, she laughs at!'" Laughing together, even in the midst of heartache, helps families to experience resilience.

Believing and Investing in Recovery

Families coped with STBI by believing and investing in recovery. As identified earlier, the work of recovery is exhausting, yet families are able to experience resilience by investing in the hope of healing.

Families chose this investment in spite of the grim prognosis and the wealth of unknowns facing them. One family articulated having to choose to invest in recovery following a difficult conversation with medical staff. "We had to decide—are we going to fight for him or are we just going to take what the doctors say?" Likewise other families identified similar experiences of choosing to put their energy into hope and recovery. "The decision's made: we're in this together and we'll fight."

One family described their drive to fight for recovery. "Five years down the road, ten years down the road, I'd like to be able to say, we did absolutely everything we could.

We did everything we know how to get her to where she can function like she is." The father went on to describe that this is not easy and some days all they can think about is the next step in front of them and just putting "one foot in front of the other."

"There have been many, many days where it has felt hopeless and… there have been many days of loneliness and being so frustrated and angry at this whole situation, but hope is this refreshing breath of fresh air," said one father.

Families identified needing to renew their commitment to healing and recovery repeatedly. For some families, they discussed needing to acknowledge each morning, "We're going to put forth this effort into her recovery." Even after bad news, families chose to believe and invest in recovery. "Again, we'd get nothing, but bad news and bad reports as to what her recovery was going to be and every time I would fall apart and somehow something inside me would just say, 'Ok, don't give up… Keep fighting.'" After a particularly grim meeting with the medical staff, one family described their reaction, "I looked at the doctor and said… 'Well, you might be right, but we serve… a God who, if it's His desire for [her] to recover and heal, that can happen and we believe that.'"

One father described the need for the hope of recovery. "Hope is an amazing thing… that's the battle I think—To find and to live with hope."

Believing and investing in recovery also involves choosing to explore and pursue creative approaches to healing including alternative therapies, and non-traditional techniques. Families sought out therapies and healing methods that, as one family put it, "believe, live, breathe and communicate that these children who suffer from these injuries can recover." Investing in recovery has both emotional and financial costs; however, choosing the hope of recovery bolsters family resilience within the trauma of STBI.

As one father put it, "How much is her recovery worth? You know, it's a pretty big sacrifice and maybe a lot of families just can't do that. And yet we're doing all we can to invest ourselves and invest in her and believe in her recovery."

Celebrating Small Victories

From the first hint of an eye opening to a twitch of a finger to the first decipherable word, the small steps forward mark the road to recovery from STBI. Progress is typically gradual and painstakingly slow. Families who experience resilience during the initial phase of crisis and trauma while their family member is in the ICU for an extended length of time will continue to rely on their resilience as the long term effects of the injury stretch out for a lifetime. Resilience through this long term is seen in the ability of families to celebrate each small step towards recovery, each small sign of healing. "What sustained me [was]… making little things [my son] was doing better seem like he just won the spelling bee or shot the winning basket in the game, getting people excited about [him] and keeping them excited about [him] so they could be part of his life and thus help his recovery…"

Resilience can be seen in one mother's commitment to celebrating even the smallest signs of healing. "I'm just going to make every single thing seem like fireworks are going off."

One family described their daughter's continued progress, "We constantly continue to see that she is improving, in micro-steps." Recovery from STBI comes in small victories. My family marked the first time my brother opened one eye, the first time he moved his tongue, the first time he smiled. Without celebrating these small steps, families can get discouraged and begin to feel as if no progress is being made at all.

Believing In and Fighting for Who S/He Was

Interconnected to celebrating the small victories, families experience resilience by believing in and fighting for who their child/sibling was. STBI, as discussed earlier, leaves families with the grief of having lost the child and sibling they had known and loved. Resilience through STBI emerges when families are able to take that loss and find the energy to fight for recovery by believing in the person their child and sibling was before the injury. One mother said, "I think for me, from the very beginning, even when she was in the hospital, still not responding and the doctor says she's never going to [wake up]… I would look at her and I believed in her."

Another mom discussed how she remembered what a "very charismatic, very funny, very cool" child her son was. "I always thought he was such a full-of-life, zingy kind of personality and… my whole thought process was—he needs to get to that point again." Parents and siblings of the injured child find energy and resilience in not only remembering who their family member was, but also using those memories to inspire the fight for recovery.

Connecting with Others

Families experience resilience by connecting with others. Beyond simply finding support (which is also part of resilience and will be discussed in the next section), connecting with others involves a two-way relationship.

One significant tool for families in order to better develop connections was the use of technology, such as Caringbridge, a website designed to help families with health issues connect to support communities via blogging. Families articulated that using technology allowed others to maintain connection to their family members recovery process even though healing was slow. Connecting also allowed others to be an encouragement to the family, which was especially important when their family member was in the hospital, and often far from home, for long stretches of time. "I could go another hour with… not even thinking of how horrible the situation was if someone wrote something positive in the [Caringbridge] guestbook to me. Or if I got to sit and write a paragraph about what just happened in therapy and got to tell jokes about it… that would just give me an upbeat attitude… Caringbridge was the best thing that ever happened to me with this accident… People lifted me up by writing things and I was lifting myself up by writing."

For some, connecting included finding other families who have walked the path of STBI. One family said that connecting with other families who had experienced STBI "gave us renewed hope even though we were also aware that it wasn't going to be easy." These families encouraged, exchanged ideas, and energized each other.

For other families, they connected by reaching out to families who needed help navigating this path, who were newly experiencing the shock of STBI. Knowing the importance of connection, one mother identified her need to reach out to others in order to help them avoid isolation, "There's not a lot of people that you can sit and visit with that really get it… To have support, someone who's been through it, that knows, is so big."

Connection with others also took the form of reaching out to other people who were experiencing health-related trauma or who knew the injured family member.

During those stressful days in the ICU, one family found "comfort in talking to family members of other people in the ICU. You could hear what they were going through and, for a little while, it took the focus off where you were walking."

Support from Family, Friends and Community

By far, the most frequently discussed factor in family resilience through STBI was the support of family, of friends, and of community. Within this broad category, two clear sub-categories emerged—the support of being and the support of doing. Families identified supporters who carried them through the various stages of dealing with STBI simply by being—through their supportive presence, through listening, through encouraging. Equally as often, families named supporters who carried them by doing—through their actions, through giving financially, through offering tangible support.

Support by being. Emotional support from extended family, friends, and community certainly fosters family resilience. This support resonates with the aforementioned category of connecting with others. This sub-category, however, attempts to encapsulate the acts of other people—family, friends, and community—to support the family, whereas the previous category of connecting with others involves the family taking action to reach outside themselves.

The immediate response of family, friends, and community played a role in fostering resilience. In the hours following the injury, families experienced shock and intense fear, yet in the midst of it, these families named the transformative power of family, friends, and community who surrounded them almost instantly. "…word seemed to spread and people in this community came to our house within minutes." Families recount stories of supporters coming from great distances just to be present with them in those initial hours of trauma.

The support by being is needed beyond those immediate days as well. Families named the ways in which, though it looks very different, support continues into the long term healing process. Upon recognizing a gesture of support by a community organization over two years after the injury, one family member exclaimed, “Wow! This support doesn’t end. I wasn’t expecting that. It just continues.”

By leaning on each other and on the support of an extended network of people, families experienced increased resilience. “Everybody broke down at one time or another, but there was always somebody there encouraging us… There was always some family member that managed to keep us strong,” said one family. “I don’t know if we ever did lost energy because somebody was always helping. Someone was always able to keep each other going. I mean, I remember times when… I could tell this is really discouraging for [someone], but there was always somebody else that was ready to go to work… The balance was incredible,” explained one father.

Repeatedly families mentioned extended family, close friends, faith communities, and neighbors that showed support by being present, and by simply being attentive to their family’s recovery. “I don’t know what I would have done without them,” exclaimed one family member. Talking about extended family who offered seemingly endless emotional support, one mom said, “Family support is huge, huge, huge!” One mother shared that visitors to the hospital would come just to talk or to listen. “It was the best couple of hours of the week where I would relax and… I just… could laugh.”

Support by doing. Because STBI calls upon a family to put their life on hold for a period of time and involves an extended stay in hospitals and care facilities, families often depend on not just the emotional support of others, but also the acts of tangible support. Financial giving, providing meals, taking care of household needs, doing research on resources and therapy, helping renovating homes to make them accessible—these are just a few of the ways that extended family, friends, and community were actively engaged in support which fostered the family's ability to cope with STBI.

"The community… really rallied around at the beginning. There were benefits so… the community raised $25,000 for us. I was able to get a van to transport [her] around," said the parents of one family.

When her son was injured just before the start of the school year, one mom was helped in many ways, including neighbors who were attentive to the needs of her other children. "People kind of just started to take care of things for us. Like my neighbor picked [my other child] up and took her school shopping."

Logistics of households such as care of other children and meals were addressed by community support. One mother said, "My mom came and moved into our house and [we] stayed at the hospital for five weeks. My mom and my best friend took turns staying each week at our house with [our other children]." Another family shared about the active support of their community, "Five months we had a supper meal every day, even after we came home." When sharing about the many ways they had been helped, one family member simply stated, "It was phenomenal to be served like that."

Following the accident, one father described the community rallying immediately to take care of their needs so they could leave for the hospital without delay. "By the time we got home [about an hour after the accident], all the arrangements were made—who was going to take us down to the [hospital, which was about four hours drive], how we were going down… and suitcases packed… and arrangements made for the kids. I don't know how it all happened, but we didn't do it… somebody took care of all that."

Families expressed that when physical needs were taken care of, they felt freed to focus on healing, on recovery, and on supporting each other. The work of dealing with STBI is exhausting and the support of extended family, friends, and community allowed families time and space to grieve, to start to find healing, and to readjust to a new normal. With needs being taken care of by support people around them, families can tend to their own healing as well as the healing of their injured family member.

For some communities, engaging in supportive action comes more easily than engaging in emotional support. One family described this within their own community, "I've noticed that our community is good at doing things—like when [we] were home by ourselves [because our parents were at the hospital with our injured sibling], they were good at bringing meals… and pulling people together to help build [an accessible] house for us. I see the community as being supportive when it comes to doing stuff, but not quite as much when it comes to emotional support."

While families noted experiencing well-meaning supportive acts that were less-than helpful, families recognized that overall the support from extended family, friends, and community was a significant part of their family's resilience. Even when communities felt uncomfortable offering emotional support, physical support, in a way, is emotional support. "When I think back, hearing the huge crowds and the [financial] total that got brought in from the fundraiser was the point at which I was able to stop worrying about how we would stay [at the hospital]. I recognized that I need [my family] around me, but I had no resources to make that possible. When I heard the total on that fundraiser… that was really huge for me. I was very aware that I was not going to be able to keep on unless [my family] were there. I just couldn't have."

Spirituality

Not all the families who participated in this study use the language of spirituality, yet an active sense of being a part of something greater than oneself was evident in all the participants' stories. Those that did use spiritual language noted a strong sense of connectedness to God, articulating that experience as a personal and intimate relationship. For many that spiritual presence was experienced through professional chaplains, for others that spiritual presence was experienced through the care and support of family and friends, for others that spiritual presence was an inner strength urging the family to fight.

"We just see [God's] fingerprints in this. I mean, we wouldn't want this situation at all… I'm not saying this has been a smooth road by any stretch of the imagination, what I'm saying is that I just feel like in the midst of a horrific situation… we have just had a lot of good [people around us]," said one father.

"I feel like there was some sort of providential divine grace that we were able to just walk through those first weeks with kind of a peace and a grace that was very, very needed," shared a mother.

When asked about the moments of re-energizing, moments of feeling sure your family could get through this, one mother spoke about a sacred Bible verse, "our favorite verse for [my injured daughter] and I is that 'in our weakness, [God's] power is made perfect.' Because we do feel pretty weak most of the time. And I don't know that I ever, or often, feel like, 'Yes, I can do this,' because I really don't feel like I can. It's only by [God's] power, grace, strength…"

The connection to an active spirituality provides a sense of hope and a way to believe in a miracle. "We still strive, strive, strive every day to just pray that God will change things for us. I just can't believe how hard she… fought." "Thankfully I do believe in miracles, so who knows what God has planned." This is not wishful thinking for these families; it's a real sense of connectedness and an active, living, moving God. "I can't make sense of what God is doing, except that I know His promise is to work out for good. That's all I know and I stand on that."

Families connect with an active spiritual presence that they describe as walking beside them. "I have hope of this situation somehow being unveiled as to what its purpose was and what God accomplished by having this family walk through this situation."

Families spoke about themselves as ordinary families, naming a sense that each day they seek grace for the day. For families this could be seeking through prayer; other families would name other activities of centering and grounding. Regardless of the language used around it, families named a need for an active presence beyond mere existence to guide them, to ground them, to keep them focused, strengthened, and gracious.

Finding Meaning

Discovering meaning beyond mere existence fosters family resilience through STBI. For participants in this study that identified as Christian, this took the language, "God has a plan." For all participants in this study, this meant they searched for ways to find meaning in their life as a family. While none of the families participating in this study assigned a reason for why their family member sustained an STBI, they did find ways to see meaning in their resilience through STBI, in their ability to connect with others, and in their newfound reliance on faith and on community.

"I realize now how God has a hand in everything your whole life…" One father experienced the loss of his employment after the accident. "The benefit was that I was able to come home for thirteen months and help [my wife]… God took care of us in that time… it gave us a time when I was able to come and be right next to [my wife] and then I was taking [our daughter] to therapies three times a week and I gained a lot of insight. She and I have a closeness now that we would've never had without the accident." While they are quick to clarify that, of course, they are not glad the accident happened, yet they have been able to find meaning beyond mere existence in the aftermath of this family trauma.

A sense of spiritual connectedness, for some families, has provided a meaning beyond existence. This takes the shape of wanting to make the world a better place. For other families it takes the shape of believing in the healing of the afterlife. "In Christ, we have hope. We have hope of his presence with us; we have the hope of him being able to turn what is awful into something that can be meaningful and a blessing. And we definitely have the hope of eternity. And you know if life is ugly and awful and… a path of suffering… the hope of heaven is all the more appealing and all the more wonderful." There's something beyond existence for these families. When existence is more painful than it should be, finding meaning that suggests there is more becomes a line to healing.

"She's giggling and she's just like a child… Uninhibited. Nobody else is giggling at the pastor [in church], but she's so excited you know, this life is short. So the meaning part is that she gives us perspective. In life."

Summary

Family resilience through STBI is marked by these eleven categories. These eleven concepts are linked to and interactive with the others, yet each distinctly emerged from the interview data. These categories intersect, and build on each other as families move through the dynamic process of dealing with STBI. Families experienced resilience by accepting the reality of the injury while also acknowledging their grief of loss, allowing family members to react uniquely, incorporating some normal back into their family life, laughing together, believing and investing in recovery, celebrating small victories, believing in who s/he was, connecting with others, receiving support from others, engaging in spirituality, and seeking meaning beyond existence.

Feedback for Social Work Practice

Lastly, the interview data was explored for specific feedback families had for social work practice. While all the results can inform social work practice, families had some specific information they suggested social workers should know about their experience through STBI. Families expressed gratefulness for the many roles social workers have played and continue to play in the lives of their injured children. Social workers helped find housing, connected families to abundant resources, advocated for services, and explained confusing medical terminology. Social workers pushed hospital administration to make things happen. "The social worker is there, not on behalf of the hospital. They are on behalf of the patient," said one mother expressing gratitude for the energy a social worker gave in advocating for her son.

One mother described the need for social workers to offer a sense of hope and without pity. "The social worker while we were at the hospital… was nice, but I always wanted to leave the room when she would come… There was always this feeling of pity. She probably meant to show care and concern, but to me it felt like [she was saying], 'I'm sorry; things are never going to get better.' Instead of breathing hope that sometime [our daughter] is going to get better… it was just this feeling, this look on her face of pity."

Another mother discussed how social workers attended to the needs of the injured child's family, not just the injured child herself. "The social worker was so wonderful because it was—What can we do for you? It wasn't so much, what can we do for [your daughter with STBI]; it was what can we do for you to make this easier for you—the caregiver." This mother went on to describe how social workers were attentive to the fact that in order for her daughter to heal, the mother needed care as well. Another mother had the opposite experience, affirming the need for social workers to note family care needs. "There needs to be someone taking care of the family in the hospital. The patient's getting all that they need, but nobody was ever checking on me."

While in the hospital, one mother discussed that social workers wanted to help her get information, but didn't seem to understand how time-consuming the hospital stay was, suggesting she read a book about TBI. "In times of crisis, don't put a… book in my hand to read." She asserted that she just wanted the strategy and did not have time to read the whole book as she was just "trying to survive."

Social workers can be key to helping families find options. “We had no idea where to start looking [for rehabilitation hospitals] or how all this works. And so I would say… any information is power and so whatever information you, as a social worker, have don’t hesitate to make it known. Put options out there for families.”

As expected, families had mixed experience with social work practitioners, yet all were eager to encourage social workers to learn more about the experience of families dealing with STBI and offer family support when possible in their roles. Families specifically wanted social workers to know: how grateful they were for their help, how important hope was for families, how helpful it was when the whole family received care, not just the injured child, and how valuable clear information and direct resources were.

CHAPTER V

DISCUSSION & CONCLUSION

The purpose of this research study is to explore the experience of family resilience through STBI so as to inform the social work profession. This chapter will take the results of this study and further discuss each research question, exploring the meaning of the qualitative findings and discussing how the quantitative findings support or do not support the qualitative findings.

Research Question 1: How have families experienced the journey of a child family member sustaining a severe traumatic brain injury?

Families expressed abundant challenges in moving through the trauma of STBI. The categories that emerged from the interviews reconstructed what families shared as the reality of their experience. Coping with STBI is long-term journey characterized by a rollercoaster of emotions, including exhaustion, grief, isolation, and vast unknowns. During this journey families must navigate complex medical settings and must face the loss of and the rebuilding of a sense of normal.

These categories emerged from the interview data and are supported by the survey data. Within the survey data, families indicated long hospital stays and a continued need for intense caregiving. Family information gathered from the survey identified a high level of caregiving still required for all the participants with an STBI, despite being between two and eleven years post-injury. The support scale identified diminishing and dynamic support. Families need continued support through the long-term, yet the support scale demonstrated both formal and informal supports moving from “very helpful and very available” in the first one to six months following injury to “somewhat or sporadically helpful support” after six months post-injury. The support scale also identified that the formal supports change. In the first month following injury, families reported high levels of support from social workers. In two to six months post-injury, the mode indicates levels of support from social workers lessened; yet modes for rehabilitation therapists showed increased support. Additionally, support from home health care and brain injury associations emerge in the two to six months after injury and show increasing supportiveness beyond six months. This demonstrates the dynamic nature of support for families within formal support settings. While support may be there for families, it requires families to learn new systems and develop new relationships in order to access that support. This sense of formal support professionals, such as social workers and therapists, having ebb and flow correlates with the participants describing this experience as a rollercoaster and is another aspect of having to navigate complex medical systems.

These categories resonate with previous research, were affirmed by one participating family and by my own experience. Previous research studies on elements of TBI echo similar articulations of this experience (Bond et al., 2003; Collings, 2008; Leith, Phillips, & Sample, 2004; Marsh, Kersel, Havill, & Sleigh, 1998; Perlesz et al., 1999; Roscigno, 2008; Roscigno & Swanson, 2011; Wade et al., 2006). In response to reviewing the categories of the family experience, one participating family wrote, “I can’t believe how well you captured what the journey is like. I guess I shouldn’t be surprised because you and your family have gone through this yourselves! I cried as I read it because it was as if you had been inside my soul. It spelled out the emotions so well." After thorough data analysis, the categories that emerged also corresponded with my own experience.

Within the findings from the interviews and follow-up emails, families made it clear that moving through STBI altered families' very existence and caused a reshaping of their identity as a family. The data showed multiple challenges intersecting and overlapping the others, leaving families confused, grieving, and struggling to move forward. Navigating these changes was never clear or easy, yet each family described a process of making it through together, even as they felt they were individually falling apart. The meaning within this data speaks to the importance of supporting families through this experience rather than just focusing on the individual who sustained the injury. The importance of attending to the whole family continues for each of these families long into recovery and long-term care. Professionals within any field working with individuals with STBI can use these categories to understand the unique challenges the family unit, beyond just the individual, is facing. The family experience of STBI was identified in the interview data and affirmed by the survey data, by participant review, and by my own experience. Dealing with STBI is painful and traumatic for families, yet families were able to move through it with resilience, with increased resources and strength.

Research Question 2: What has resilience looked like for these families and what fostered family resilience during their journey?

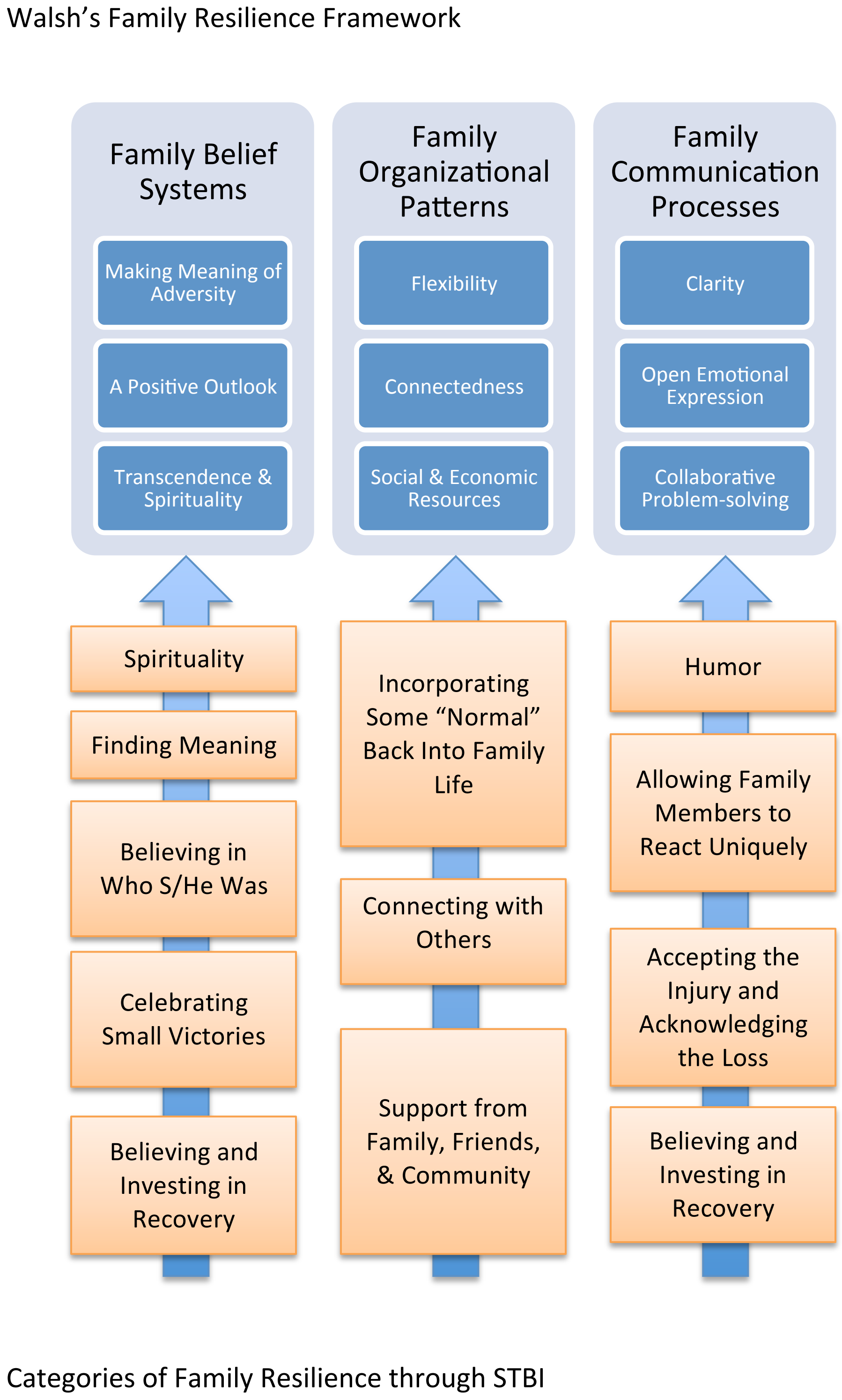
The families in this study experienced STBI within their family, yet were able to emerge from that trauma with resilience. This resilience was identified through the use of the FRAS and materialized, according to qualitative data, in the ability of families to accept reality while also acknowledging loss; to allow family members to react uniquely; to incorporate some family norms back into their lives; to laugh together; to believe and invest in recovery; to celebrate small victories; to believe in who their family member was before the injury; to connect with others; to receive support from others; to experience spirituality; and to find meaning beyond existence. The support of these elements of resilience, or the lack thereof, can either foster or hinder the family's ability to experience resilience through STBI. The results of the data analysis demonstrated these findings and the survey data and Walsh's family resilience framework support these findings.

The FRAS showed families participating in this study as having high resilience, especially considering the trauma of having been through STBI. The reliability of the FRAS tested high, indicating a consistent scale. The use of the scale offers a quantitative picture of resilience; as the mean of the participating families was above the scale mean score, indicating a high level of resilience even as families were immersed in discussing a particularly painful trauma. Once the presence of resilience was established, the interviews and follow-up emails gathered data that informed what that resilience looked like for these families.

Walsh’s family resilience framework validates the results of the data analysis. The categories of resilience through STBI that emerged from this study are congruent with and complimentary to the processes and subconstructs within Walsh’s family resilience framework. The eleven categories of resilience all fit within and capture the three processes within family resilience framework: family belief systems, family organizational patterns, and family communication processes.

The discussion of how these categories fit with family resilience framework follows. By exploring the connections between this study and family resilience framework, the findings of this study are validated by the years of research and practice affirming family resilience framework. Additionally, the connection between the categories and the framework suggests that family resilience framework is a useful tool for social workers practicing with families facing STBI.

Figure 5. Family Resilience Framework & Categories of Family Resilience Through STBI



This study identified five categories of family resilience through STBI that fit within the concept of family belief systems—Spirituality; Finding Meaning; Believing in Who S/He Was; Celebrating Small Victories; and Believing and Investing in Recovery. These five categories echo the concept within family belief systems. In these five categories, families found positive messages in the midst of their painful surroundings, sought out spirituality and transcendence, and were able to create meaning beyond their own existence.

Three categories emerged that resonate with family resilience framework's concept of family organizational patterns. These categories are: Incorporating Some "Normal" Back Into Family Life; Connecting with Others; and Support from Family, Friends, and Community. Within these categories, families demonstrated flexibility, connectedness, and found social support. By utilizing family organizational patterns, families were able to experience resilience in the face of the pain and trauma of STBI.

There were four categories of family resilience through STBI that fit well with family resilience framework's concept of family communication processes. Humor, Allowing Family Members to React Uniquely, and Accepting the Injury and Acknowledging the Loss are all ideas that resonate with family communication. Additionally, the category of Believing and Investing in Recovery also resonates with family communication processes as well as the aforementioned family belief systems. These four categories encapsulate the family's ability to use clear communication, open expression of emotions, and collaborative problem solving to develop their resilience and move through this trauma well.

In summary, the data analysis of the family experience of resilience through STBI demonstrated reliable results. Upon further discussion, it was evident that the eleven categories of family resilience emerging from this data set are congruent with the family resilience framework concepts developed by Walsh (1998). These findings indicate the ability of families to make it through even the complicated trauma of STBI. Families need support and much of the support and healing they need can be found within themselves as a family and within their own communities. Resilience emerged, not as a static characteristic of families; instead resilience emerged as a dynamic, messy process with ebbs and flows, and ups and downs.

Implications for Social Work

This study of family resilience through the experience of STBI demonstrated both the challenges families face as they struggle to cope with STBI and how families have experienced resilience even in the midst of that trauma. Social workers can use the work of this research study to inform their practice with families experiencing STBI in a variety of practice settings.

Social workers will come across families dealing with STBI in a variety of settings—school, social services, hospital, and mental health settings, to name a few. Social workers can use the emergent results on the family experience of STBI to develop a groundwork for understanding the family's experience. Additionally, and perhaps more importantly, social workers can use the categories of resilience to inform how to develop practice with families. Social workers must begin to recognize, acknowledge, and foster resilience within families by working through a resilience lens. This lens can be applied within all practice settings from working with families to developing policy.

Families moving through the trauma of STBI need the support of knowledgeable and attentive social workers, from the hospital to long-term care. Families dealing with STBI are struggling with an unusually complicated trauma that most professionals, including social workers, are not prepared to support (Roscigno, 2008). In order to grasp and understand this experience, those in the service system must start by allowing those who have been through this trauma to speak to what the experience is and how resilience emerges. Families need the support of social workers who understand their experience, and, perhaps more importantly, who understand and recognize resilience. Within practice settings, social workers can use this study to grow their knowledge as they work alongside and attend to families who are experiencing STBI.

This study brings to light the understanding that resilience, like most human endeavors, is nonlinear and dynamic and therefore requires careful attention. The constructs of resilience identified in this study are organic elements within families that social workers can encourage and illuminate. These elements are ever-changing and, without the lens of resilience, may go unnoticed. Social workers who are able to identify and bolster these resilience constructs can breathe hope and healing into families as they struggle to move through the trauma of STBI. In my own experience, professionals who worked alongside my family often saw their role as needing to force my family to "face reality" or to combat false hope. We spent considerable energy just holding on to hope for healing. Participants in this study echoed this desire for professionals that breathe hope, professionals that respect each family's journey, and professionals that look for and build on the elements of resilience that are emerging from within the family. Social workers and professionals can increase family well-being by attending to resilience.

Because resilience is nonlinear and dynamic, it requires that social workers carefully listen and observe through the lens of family resilience.

Family resilience framework resonates as a powerful tool for working alongside families who have experienced STBI. Social workers can become familiar with family resilience framework to guide all levels of practice. By using family resilience framework, social workers can actively be a part of bolstering family resilience. Social workers have an obligation to the strengths perspective and to finding ways to foster family resilience. They can begin to do so by utilizing Walsh's family resilience framework as they work with families, especially with families who have experienced STBI.

Limitations of the Study

The design of this study involved participants from five families who were known to me, and for whom the injured child was a teenager. Further research studies with a larger sample, with variation in language, or with mixed ages of injured children might provide different insight into family resilience through STBI. Convenience sampling brings with it limitations in participant selection and cannot guarantee a representative sample. However though the sample size was small and taken from my own contacts, these two elements allowed for in-depth interviews and a level of comfort with participants that may not have been possible otherwise. Families shared openly being somewhat familiar with me and knowing that my own family had travelled the journey of STBI. That said, the connection of the family to me previous to the study certainly shaped their responses. It is my hope that this connection only allowed for greater depth and more honest responses. As a researcher, I encouraged families to share freely with the assurance of confidentiality, yet it is possible that families may have shared specific pieces of their journey differently as a result of my connection to them.

The design of the sampling was such that the results of the study cannot necessarily be generalized beyond the participants in this study. The aim of the study is exploration, seeking only to explore this lived experience. As such, it was not intended to be used as a blanket statement to apply to all families experiencing STBI. Indeed such generalization perhaps would only serve to minimize and de-humanize an experience that is deeply personal and unique to each family. Instead, this project is intended to guide professionals to a beginning understanding of the family experience of STBI and of resilience in the midst of it and to encourage practitioners to consider the family experience and resilience in their practice.

Participants were asked to respond to survey and interview questions as a family unit, yet it is impossible to ensure that responses truly took the family as a unit into account. To minimize this issue, families were reminded of this expectation in writing and verbally throughout their participation in the study.

Lastly, my own family's experience of STBI presented at times a limitation to this study. During the course of this project, my process of healing from this same journey compelled me to avoid the project for days at a time. Knowing this personal experience would cause challenges to the work, I worked to stay cognizant of my own reactions and my own internal gauges. I found that my own experience, in many ways, added a greater depth and validity to the project. For example, it struck me repeatedly in each interview how short 90 minutes would be if I did not already know intimately the language and culture around STBI, such as medical terms and the processes of recovery. Due to my first-hand knowledge, I was able to understand and gather more of the participant's story. This added to the project as I knew the data I collected contained significant depth. At times this closeness to the project caused my research to slow, yet it has resulted in a rich project—a project my experience has bolstered rather than hindered. Even so, the work of this project is certainly affected by the lens through which I see the world as a result of my experience with STBI.

Future Research

There continues to be a need for more qualitative research on STBI and especially on the family experience of this trauma. Research studies in which family resilience is observed as well as articulated and studies with larger sample sizes would allow for a new and more complete perspective. Additionally, studies exploring the specific elements of resilience would add greater depth of understanding to the processes of family resilience.

Research can continue to discover which modalities are most effective in working with families. How can social workers best help families navigate this experience? Beginning with a resilience lens and understanding the experience is a solid start, yet practitioners will continue to need research-informed intervention and practice methods. Additionally, continued research to develop tools, such as the FRAS, for resilience practice would benefit social workers implementing resilience frameworks.

Concluding Remarks

In summary, this exploratory research study demonstrated the challenges families face when dealing with STBI and illuminated the ways in which resilience emerges for these families. Creating and implementing this research study has been a tremendous journey. As families shared the deep grief of their journeys, the great celebration of the steps of recovery, the heart-wrenching ache of continued loss, and the hope of loving communities, it became abundantly clear that this experience needs to be shared. Practicioners must understand the specific and complicated nature of this experience and they must support families in building their resilience through it. This process of building resilience will likely never be easy—for the individual with the injury, for the family, nor for the practitioner. Yet it is this process that fosters the well-being of families as they face a complicated and overwhelming trauma. Social workers and support professionals have a unique opportunity to breathe hope for these families, to offer a perspective that illuminates their resilience, and to offer support knowing that resilience and healing is not always linear, nor pretty, nor obvious. It is my hope that this project can encourage social work practitioners to utilize the concept of resilience and to be cognizant of families dealing with STBI in their practice in authentic and hopeful ways.

APPENDICES

Appendix A
Contact Email

(Participant Name),

I am currently in the midst of my graduate studies in Social Work at the University of North Dakota. Because TBI has, in a sense, taken over my life as Landon recovers, I have decided to focus on TBI for my final research project.

My research project is exploring the topic-- The Experience of Family Resilience Through Traumatic Brain Injury. Meaning I am looking at how families make it through the trauma of a severe TBI and what fosters their resilience.

In this project, I want to interview families (including my own) that have walked this painful, gut-wrenching journey. And I would be honored if you (and your family) would be willing to be a part of it. The research will be two parts: one written survey-type section and a recorded interview (via phone or Skype). The first part should take less than 30 minutes and the second should take 60-90 minutes. I will give you the questions for the interview ahead of time so you won't be expected to come up with answers on the spot. And I wouldn't expect your whole family to be present for the interview-- just whomever from your family is willing and able. It could be just yourself or the whole clan. My goal is to capture your family's story and to use these stories to inform the social work profession about how to best support families who face this experience.

If you are willing to help me out in this way, I would be wildly grateful and would be (of course) committed to honoring your family's journey in my work. There will be no wrong answers, of course. And you are welcome to see the written report when it's done (or even in the editing phase, if you wish). I am looking to complete the entire project by June and would like to have the interviews and surveys completed in the next month or two.

Please let me know if your family would be willing to be a part of this work. If you are, I will send you more information and will set up a time that works for you and your family for the interview portion.

Thanks,
Shanda Hochstetler

Appendix B
Consent Form

The Experience of Family Resilience Through Traumatic Brain Injury: A Mixed Method Study

Shanda Hochstetler * (503) 729-5263 * Dept of Social Work

Because your family has been through the experience of having a child sustain a severe traumatic brain injury, you, as a family, have been invited to participate in a research study about family resilience through the experience of severe traumatic brain injury.

The purpose of this research study is to take a closer look at how a family is able to demonstrate resilience through the crisis of a severe traumatic brain injury. This study hopes to better inform the social work profession about what makes families resilient as they cope with severe traumatic brain injury.

Your participation is voluntary. You may choose not to participate or you may discontinue your participation at any time without penalty. Your decision whether or not to participate will not affect your current or future relations with the University of North Dakota.

A person participating in this research must give his or her informed consent to such participation. This consent must be based on an understanding of the nature and risks of the research. This document provides information that is important for this understanding. Research projects include only subjects who choose to take part. Please take your time in making your decision as to whether to participate. If you have questions at any time, please ask.

Seven families will be invited to take part in this study, which will be completed in two phases.

The first phase will be the completion of a survey. This can be done online or on paper, whichever your family prefers. You will be asked to respond to questions as a family unit about your family's demographics and your family's experience with severe traumatic brain injury.

The second phase will be the completion of an interview with the researcher via Skype, an internet-based video phone service. Skype is available free of charge. Any members of your family are welcome to participate in this interview. You will receive the interview guide at least two weeks before the interview is scheduled to allow you time to gather responses from family members who may not be able to attend the interview, and to allow you time to think about your answers. As with the survey, you will be asked to respond to questions as a family unit. The interview will be recorded. You have the right to review the recording at any time. The researcher and project advisor will have access to the recordings. All recordings will be destroyed 3 years following the study. In both phases of the study, you are free to skip any questions that you would prefer not to answer.

Your participation in the study will last approximately 2 hours in total. The first phase (the survey) will take approximately 30 minutes, and the second phase (the interview) will take approximately 90 minutes. Both phases can be completed in your own home.

The risk involved in this study is minimal. You and your family members may have emotional reactions while remembering and reflecting on your family's experience. During both phases of this study, you may stop at any time, ask the interviewer to take a break or chose not to answer a question. If you need extra support, the interviewer will have information about available mental health resources in your community.

You will not benefit directly from being in this study. However, this study will improve awareness in the social work profession about how to better support families who are dealing with severe TBI. As a result, your participation could help others in the future. If you wish to have a copy of the completed research study report, please just let the interviewer know.

You will not have any costs for being in this research study. You will not be paid for being in this research study. The University of North Dakota and the research team are receiving no payments from other agencies, organizations, or companies to conduct this research study.

The records of this study will be kept private to the extent permitted by law. In any report about this study that might be published, you will not be identified. Your study record may be reviewed by Government agencies, and the University of North Dakota Institutional Review Board

Any information that is obtained in this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Data will be stored securely in the office of the researcher. If we write a report or article about this study, we will describe the study results in a summarized manner so that you cannot be identified.

If you have any questions, concerns or complaints regarding this research, please contact the researcher, Shanda Hochstetler, by phone at (503) 729-5263 or by email at shanda.hochstetler@und.edu. Additionally, you may contact the project advisor, Dr. Andrew Quinn at the Department of Social Work, University of North Dakota, 225 Centennial Drive, Stop 7135, Grand Forks, ND 58202-7135; phone: (701) 777-4568; email: andrew.quinn@email.und.edu.

If you have questions regarding your rights as a research participant, or if you have any concerns or complaints about the research, you may contact the University of North Dakota Institutional Review Board at (701) 777-4279. Please call this number if you cannot reach research staff, or you wish to talk with someone else.

Thank you for taking the time to be a part of this study.
Shanda Hochstetler
University of North Dakota

Adult members of the family:
Your signature indicates that this research study has been explained to you, that your questions have been answered and that you agree to take part in this study. You will receive a copy of this form.

Adult Subject's Name: ____

___________________________________ ______________
Signature of Subject Date

Adult Subject's Name: ____

___________________________________ ______________
Signature of Subject Date

For children in the family age 13-18:
I have read and understood the research project explained on page 1-2. Anything that wasn't clear to me was explained so I could understand it. If I have any other questions later, I can have these answered too. I understand that I don't have to help with the project even if my parent(s) or guardian(s) say that it is all right. Even if I decide to do the things I will be asked to do, I can change my mind later and that will be OK. I have decided I want my family to help with the project.

Child Subject's Name: ____

___________________________________ _______________
Signature of Subject Date

Child Subject's Name: ____

___________________________________ _______________
Signature of Subject Date

Child Subject's Name: ____

___________________________________ _______________
Signature of Subject Date

(For children that cannot read, please read the following to them.)
For children in the family age 12 and younger:
We are doing a research study; a research study is a special way to find out about something. We are trying to find out what it is like to have a family member with a brain injury.

If you want to be in this study, we will ask you to do several things. Your family will be writing some answers and then talking with a researcher about what happened when the person in your family got a brain injury. Your family may share about what they saw you experiencing. You may choose to talk with the researcher and you may choose to help your family members with writing. You may also let your family talk for you. How much you want to be a part of this study is your choice.

Not everyone who is in this study will benefit. A benefit means that something good happens to you. We don't know if you will benefit. But we hope to learn something that will help other people some day.

When we are done with the study, we will write a report about what we found out. We will not use your name in the report.

You do not have to be in this study. It is up to you. If you want to be in the study, but change your mind later, you can stop being in the study.

If you want to be in this study, please sign your name.

Child's name (printing is OK) Date

> ***I certify that this study and the procedures involved have been explained in terms the child could understand and that he/she freely assented to participate in this study.***
>
> ***Signature of Person Obtaining Assent Date***

Child's name (printing is OK) Date

> ***I certify that this study and the procedures involved have been explained in terms the child could understand and that he/she freely assented to participate in this study.***
>
> ***Signature of Person Obtaining Assent Date***

Child's name (printing is OK) Date

> ***I certify that this study and the procedures involved have been explained in terms the child could understand and that he/she freely assented to participate in this study.***
>
> ***Signature of Person Obtaining Assent Date***

Appendix C
Survey

PART ONE

SURVEY

(Please respond on behalf of your family for all questions. Consider how your family, as a whole, would answer. You can choose who is defined as "your family.")

Family Information

Family/Last Name(s):

First names, roles (such as: father, brother, step-mom, etc) and **current ages** of all immediate family members whom you will be considering when reflecting on your family's experience with TBI:

____

____

____

____

Contact information for head of family

Name:____

Email:_______________________@________________________

Phone: (cell)__________________ (home)_______________________

Address (just city and state):___________________________________

Has there been in changes in family structure between the time of accident and now?

If so, explain changes:

Information on TBI and your family member with TBI

Who, in your family, sustained a severe TBI? (Name and age at the time of injury) ____

When did the TBI occur? (Date) _______________________

Briefly, what were the circumstances around the injury (ex: vehicle accident, sports injury, etc)?

For approximately, how long was your child in a coma? ________________

Immediately following the injury, please indicate the medical units where your family member with TBI stayed and the time spent in each and the distance from your home.

Unit *(Check all that apply)*	Time Spent	Distance from Home *(Approx)*
☐ Intensive Care Unit (ICU)	_________	___________
☐ Trauma Step-down Unit	_________	___________
☐ Inpatient Rehabilitation Unit	_________	___________
☐ Outpatient Rehabilitation Unit	_________	___________
☐ Other (Please specify unit)		
_______________________	_________	___________
_______________________	_________	___________

Approximately, how many hours of caregiver assistance (by family members or home health aides) per day does your child **currently** need to complete activities of daily living? _________

Is the family member currently living in your family home or in another setting? Please indicate the setting, if not in your family home.

____

Rate the level of support your family received from the following sources. Consider how well the support helped your family to cope with severe TBI. Please fill in each box with a number (1-5) or NA as outlined below.

Scale

1: *Unsupportive* **2:** *Little support or unhelpful support* **3:** *Somewhat or sporadically*
helpful support **4:** *Available and helpful support* **5:** *Very helpful and very*
available support

NA: *This support was not applicable to our family at this stage because it did not exist, we did not interact with this support or we did not want this support.*

	Before TBI	**First month following TBI**	**2 to 6 months following TBI**	**Beyond 6 months after TBI**
Informal Supports				
Faith Community/Church				
Paternal Extended Family				
Maternal Extended Family				
Neighbors				
Friends				
Civic community				
Formal Supports				
Nursing Staff				
Doctors				
Rehabilitation Therapists				
Social workers				
School system				
Counselors and Family Therapists				
CaringBridge				
Home Health Care				
State or National Brain Injury Association				
List and rate other supports below:				

*If you have comments or explanation that you would like to note regarding the above scale, please do so here:

FAMILY RESILIENCE ASSESSMENT SCALE, page 1

(Again, please respond on behalf of your family for all questions. Consider how your family, as a whole, would answer. Check one box for each statement.)

		Strongly Agree	Agree	Disagree	Strongly Disagree
1	Our family structure is flexible to deal with the unexpected.				
2	Our friends value us and who we are.				
3	The things we do for each other make us feel a part of their family.				
4	We accept stressful events as part of life.				
5	We accept that problems occur unexpectedly.				
6	We all have input into major family decisions.				
7	We are able to work through pain and come to an understanding.				
8	We are adaptable to demands placed on us as a family.				
9	We are open to new ways of doing things in our family.				
10	We are understood by other family members.				
11	We can ask neighbors for help and assistance.				
12	We attend church/synagogue/mosque services.				
13	We believe we can handle our problems.				
14	We can ask for clarification if we do not understand each other.				
15	We can be honest and direct with each other in our family.				
16	We can blow off steam at home without upsetting someone.				
17	We can compromise when problems come up.				
18	We can deal with family differences in accepting a loss.				
19	We can question the meaning behind the messages in our family.				
20	We can solve major problems.				
21	We can survive if another problem comes up.				
22	We can talk about the way we communicate in our family.				
23	We can work through difficulties as a family.				
24	We consult with each other about decisions.				
25	We define problems positively to solve them.				

FAMILY RESILIENCE ASSESSMENT SCALE, page 2

		Strongly Agree	Agree	Disagree	Strongly Disagree
26	We discuss problems and feel good about the solutions.				
27	We discuss things until we reach a resolution.				
28	We feel free to express our opinions.				
29	We feel good giving time and energy to our family.				
30	We feel people in this community are willing to help in an emergency.				
31	We feel secure living in this community.				
32	We feel taken for granted by family members.				
33	We feel we are strong in facing big problems.				
34	We have faith in a supreme being.				
35	We have the strength to solve our problems.				
36	We keep our feelings to ourselves.				
37	We know there is community help if there is trouble.				
38	We know we are important to our friends.				
39	We learn from each other’s mistakes.				
40	We mean what we say to each other in our family.				
41	We participate in church activities.				
42	We receive gifts and favors from neighbors.				
43	We seek advice from faith advisors.				
44	We seldom listen to family members concerns or problems.				
45	We share responsibility in the family.				
46	We show love and affection for family members.				
47	We tell each other how much we care for one.				
48	We think this is a good community to raise children.				
49	We think we should not get too involved with people in this community.				
50	We trust things will work out even in difficult times.				
51	We try new ways of working with problems.				
52	We understand communication from other family members.				
53	We work to make sure family members are not emotionally or physically hurt.				

Appendix D
Interview Guide

PART TWO

INTERVIEW GUIDE

- Tell me about who is in your family.
- Tell me about what happened when your family member sustained a severe TBI—the immediate hours and days following the injury, your response as a family.
- What kind of adjustments did your family make in the months following the injury?
- In the chaos of trauma, how was your family able to find meaning?
- Before TBI, how would you describe yourselves as a family?
- After TBI, how would you describe yourselves as a family?
- How would someone who knows your family well describe the changes in your family following TBI?
- Describe a time after your family member sustained a TBI when your family was not coping well.
- Describe a time after your family member sustained a TBI when your family was coping well.
- When your family feels overwhelmed, how are you able to keep going?
- What else would like to tell me about how your family stayed strong despite what you have faced?
- How has this experience of sTBI affected your family structure?
- What strengthened your (spirituality, social resources) during this time? What damaged them?
- What else would you like to let social workers know about how your family was able to cope with severe TBI?

Appendix E
Discovery Sheet

DISCOVERY SHEET—

humor

it changed our family

celebrating small victories

faith

loss

processing

sadness

unknowns

meaning in suffering

acceptence

confusion

poor prognosis

HOPE

isolation

unfair

putting life on hold

allowing emotions

family support

diminishing support

grief

believing in injured person

emotional support

scripture

community support

loss of normal

supportive medical staff

anger

structure

ADVOCATING

technology

not knowing how to ask Qs

unfairness

financial support

fighting

Advocating

Appendix F
List of Codes and Categories for the Family Experience of STBI

Codes	Categories
It changed our whole family. Family structure and routines Changed our recreation Sibling relationships We struggled to re-define family roles. Living far from home during hospital stays Our family no longer connected in the same way. Life on hold Our families needs shifted Focus on the injured family member Loss of freedom and “normal” development It’s hard to balance moving forward	Loss of & Rebuilding of Normal
Loss of dreams Loss of who our child was Memories Facing choices of life and death for our child Feeling helpless Jealousy of other families Poor prognosis Confusion Hoping and grieving at the same time Random accident It’s not fair! Anger and sadness mixed together Broken, achy, painful feeling Unknown future Depression	Complicated Grief
Costs a lot of money, time, and energy Coordinating medical care Long hospital stays far from home You’re never totally gone. Having someone so dependent on you is wearing “I couldn’t eat. I couldn’t sleep.” Sacrifices I had nothing left. Home renovations for accessibility	Exhaustion
Making decisions while in shock I thought we were making progress Facing possible death We were so confused It felt so surreal Just when we thought we were making progress, things would take another confusing turn It was chaos One minute we were optimistic; the next we’d hear the worst	Rollercoaster of Emotions

Codes	Categories
Others don’t and can’t understand Our other children are busy with their own lives Hard to connect People don’t know what to say We don’t know anyone else who has been through this My regular life was on hold We aren’t sure how to ask for help Different than having a disability from birth Support diminishes	Isolation
Confusion Maybe we trusted when we shouldn’t have Feeling ignored and misunderstood Speaking up Negating what we experienced Feeling in opposition with medical personnel Conflicting messages Learning to advocate Bureaucracy Now I know what questions to ask Transparency Trust Feeling powerless Grateful	Navigating Complex Medical Settings
Trying to comprehend Others with STBI have very different outcomes Not knowing anyone else who had been through this It wasn’t like the movies. Trying to make plans without knowing what the prognosis is Unique nature of STBI prognosis No idea what’s going to happen next Waiting for information Medical unknowns	Unknowns
Progress is slow. Even long after the accident, we still re-live those feelings. We couldn’t comprehend how long of a journey this would be. We’re still fighting years later. The challenges change as time goes on—some are easier; some are harder.	Long Road

Appendix G
List of Codes and Categories for Family Resilience through STBI

Codes	Categories
“I’ve got to get him back to that.” Seeing hints of who he was “This girl was a fighter.” Remembering who she was “I believed in her.” Fighting for who she used to be	Believing in Who S/He Was
Celebrating small steps Seeing “firsts” Hope Seeing miracles Micro steps Trying new approaches	Celebrating Small Victories
We’re an average family. We’re not special. We did what we had to. Schedule/organization Family structure Maintaining family traditions Desire to develop “normally” Changing expectations Used the same approach to parenting after the injury Finding ways to be normal Returning to a new normal	Incorporating Some “Normal” Back into Family Life
Humor Joking about “dark” topics Using humor as family connection Seeing humor within the effects of the injury	Laughing Together
Faith Not afraid of death Faith in the midst of depression Only God’s grace makes us strong Relationship with God Seeing God in the shock of the injury Prayer God’s providence God being in the midst of the pain	Spirituality
Acceptance “I can’t change what happened.” Facing the truth Faith and acceptance Determined to make it Tomorrow is unknown, so you just live in today Accepting her as she is Emotional openness Accepting emotions as normal The importance of dealing with the injury	Accepting the injury and Acknowledging loss

Codes	Categories
Using medication Sibling development and guilt for changing Sibling anxiety Different family members supported us at different levels	Allowing Family Members to React Uniquely
Support of people who'd been there Getting others excited about his recovery Connecting with families in ICU Helping others Talking with other people Writing and connecting with people Coping by writing Caringbridge Using technology "You can't do it alone."	Connecting with Others
Faith Seeing the positive God's direction Working together Trusting God Meaning in suffering God has a plan Belief in God Life as a gift Looking for the positive	Finding Meaning
Unexpected long term community support Immediate community response Friend support Keeping each other going The whole family was there "We had quite a community gathered here." Intense support at the beginning Family support Surrounding her with people who believe in her Extended family The importance of family support in order to cope "Family's huge. Absolutely huge." Leaning on each other Close family	Emotional Support from Family, Friends, & Community
Arrangements were made People took care of our needs Financial support Took the financial burden off Fundraisers Fighting insurance for us Cost of caring for the injured Meals provided Difference between "doing" support and "being" support Logistics and visits Community support Creative support Family support Logistics in the midst of shock	Financial and Logistical Support from Family, Friends, & Community

Codes	Categories
Sacrifice and fighting for recovery Seeing options Therapeutic creativity Importance of care the focuses on recovery Fighting for care Putting forth effort for recovery Hope Believing Frustration, but still believing the best Need for hope Inner strength in spite of poor prognosis Hope overcomes the anger and frustration Trusting my instincts Medical advocacy Deciding to fight Put everything else on hold	Believing & Investing in Recovery

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